



Maternal PKU and Pregnancy

OTIS – Preventing birth defects through education and research:

<http://www.ctispregnancy.org/pdf/pku.pdf>

University of Washington – PKU Clinic:

http://depts.washington.edu/pku/pro_info/protocols/pregnancy.html

March of Dimes:

<http://www.marchofdimes.com/>

PacNorgg:

<http://www.mchneighborhood.ichp.edu/pacnorgg/publications.htm>

Contraception

Planned Parenthood:

<http://www.plannedparenthood.org>

Contraception.net:

<http://www.contraception.net>

PKU

National PKU News:

<http://www.pkunews.org/>

Children's PKU Network:

<http://www.pkunetwork.org/>

National Coalition for PKU and Allied Disorders:

<http://www.pku-allieddisorders.org/>

PKU Clinic – University of Washington:

<http://depts.washington.edu/pku>

Your Genes Your Health

<http://www.yourgenesyourhealth.org/pku/whatisit.htm>

This brochure is available with the video, "Maternal PKU: Choices You Can Live With" at the Children's PKU Network:

3790 Via De La Valle Suite 120
Del Mar, CA 92014

Or the PKU Action Group website

<http://depts.washington.edu/pku/pag.html>

I have PKU.
Can I have a healthy baby?
What choices do I have?

Choices
You
Can
Live
With



The video MATERNAL PKU: "Choices You Can Live With" and this brochure were produced by the PKU Action Group, whose mission is to provide education and programs to support families with PKU, and the University of Washington.



The American Legion Child Welfare Foundation provided funding for this project.

What You Should Really Know

Are You Thinking About Being A Mother?

When you have PKU, becoming a mother is a very important decision.

PKU is a genetic disorder where your body does not break down phenylalanine, a component of protein. If it builds up in your body, you may have problems with your thinking and social skills. So if you are thinking about having a baby, ask for advice. Talk to people who are experts about PKU.

Can I Have A Healthy Baby?

All pregnancies have risk, but with PKU the risk is much higher. The medical community is still learning about maternal PKU.

We do know that the baby's brain and heart develop very early. If you are pregnant, protein is concentrated in your unborn child and higher phe levels can be dangerous. Your baby's phe levels are 1 1/2 times greater than yours. Babies with high phe levels can have heart defects, brain damage, and mental retardation. That's why you have to be careful to keep your phe levels very low, in order to have the best chance for a healthy baby.

Do I Need To Plan Ahead?

Yes, it is very important to plan ahead. The most important thing is to get your phe levels near 2, preferably for six months before you get pregnant. This gives you and your body time to adjust and prepare. With higher phe levels, your baby can be permanently damaged even before you know that you are pregnant. Any pregnancy has risk, but with PKU a pregnancy is always high-risk, and an unplanned pregnancy should be considered a medical emergency.

Will My Baby Have PKU?

Your baby can have PKU only if the father is also a carrier for PKU. But even if the baby does not have PKU, the baby's health is still affected by your own phe levels before and during pregnancy.

What Other Choices Do I Have?

Many women with PKU find it too hard to keep their phe level as low as 2. Some choose to adopt or not have children of their own. Talk to a genetic counselor to learn about your options. With help, you can make a good choice.

Pregnancy Checklist

(Special considerations for women with PKU are in blue)

To ensure a healthy baby :

- ✓ See a genetic counselor and discuss your plans BEFORE becoming pregnant.
- ✓ Be ready to make an educated decision affecting you, your partner, and your child.
- ✓ Have a supportive family structure.
- ✓ Be educated about the risks and responsibilities of pregnancy and parenthood.
- ✓ Have insurance coverage or financial assistance.

To get physically prepared :

- ✓ Have a physical exam – Visit your family doctor and PKU doctor to discuss your plans to become pregnant.
- ✓ Reach and maintain a blood level of 2 mg/dl (120 mcmol/l).
- ✓ Make sure that all immunizations are up to date.
- ✓ Have a dental exam so all x-ray procedures and fillings are complete before pregnancy.

When you are pregnant :

- ✓ See your doctor as soon as you think you are pregnant.
- ✓ Ask your PKU doctor and nutritionist for PKU diet guidelines for pregnancy.
 -
- ✓ Eat a balanced diet; you may need approximately 300 more calories per day.
- ✓ Get regular exercise and rest.
- ✓ Keep all appointments with your doctor and nutritionist.
- ✓ Arrange for prenatal classes.
- ✓ Do not smoke, use alcohol or drugs not prescribed by your doctor.
- ✓ If you have a cat, do not clean out the litter box. Cats can carry toxoplasmosis, and this infection can cause brain damage in the fetus or cause you to miscarry.
 -

Know and report any signs of pregnancy complications to your doctor :

- Fluid leaking or bleeding from the vagina
- Blurred vision
- Headaches or dizziness
- Sudden swelling of face and hands in the third trimester

Your
Choices
Make All The
Difference