



[www.mi.gov/newbornscreening](http://www.mi.gov/newbornscreening)

## Michigan Resources & Support

**Children's Hospital of Michigan  
Metabolic Clinic**  
Toll-free: 1-866-44CHMMC

**Children's Special Health  
Care Services**  
Family Phone Line  
Toll-free: 1-800-359-3722

**Early On® Michigan**  
Toll-free: 1-800-EARLY ON  
[www.1800earlyon.org](http://www.1800earlyon.org)

**Michigan Genetics Connection**  
[www.migeneticsconnection.org](http://www.migeneticsconnection.org)

**Michigan Newborn Screening**  
Follow-up Coordinator  
Toll-free: 1-866-673-9939  
E-mail: [MDCH-newbornscreening@michigan.gov](mailto:MDCH-newbornscreening@michigan.gov)

**Michigan NBS Parent Liaison**  
Toll-free: 1-866-673-9939  
E-mail: [NBS-parent@michigan.gov](mailto:NBS-parent@michigan.gov)

**Michigan PKU Website**  
[www.michigan-pku.org](http://www.michigan-pku.org)

## National Resources & Support

**Children's PKU Network**  
[www.pkunetwork.org](http://www.pkunetwork.org)

**Family Village**  
[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

**GeneReviews**  
[www.genetests.org](http://www.genetests.org)

**Genetic Alliance**  
[www.geneticalliance.org](http://www.geneticalliance.org)

**March of Dimes**  
[www.marchofdimes.com](http://www.marchofdimes.com)

# What is Phenylketonuria (PKU)?

PKU is an inherited disorder in which the baby is unable to use a certain part of protein (phenylalanine) found in food and milk. PKU occurs in about 1 in 8,800 Michigan newborns. Without treatment, phenylalanine will build up in a baby's body and mental retardation will result.

## How may PKU affect my child?

### Developmental Delay and Mental Retardation

Mental retardation will occur if a child with PKU does not begin a special diet within the first 7 to 10 days of life. If the special diet is started at the correct time and followed properly, a child should not have mental retardation due to PKU.

### Diet

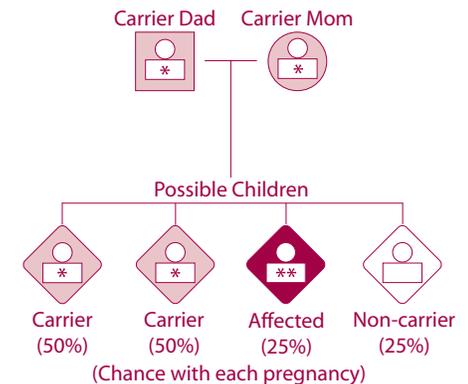
A special formula restricting phenylalanine must be started as soon as possible. Special food and formula are available for a child with PKU. The special diet should be followed throughout life.

### Pregnancy

It is vital for a woman with PKU to understand the importance of staying on her special diet before becoming pregnant. A woman who becomes pregnant while off of her diet has a high risk for having a baby with mental retardation and birth defects. Continued use of the special diet will allow a normal chance for healthy children.

## How does PKU occur?

PKU is a genetic disorder. Parents of an affected child carry a genetic trait causing PKU. Both parents pass the trait to a child with PKU. There is a 1 in 4 chance that each child will have PKU when both parents carry the trait for the disorder.



## How is PKU treated?

Newborns are placed on a special formula to restrict protein. The Metabolic Clinic will help you begin and keep your child on a special diet that meets his or her metabolic needs. Frequent monitoring of your child's phenylalanine level is needed to make sure it is in the safe range. The Metabolic Clinic and your pediatrician will help you with all aspects of your child's PKU care. A support parent is also available to help with practical tips on raising a child with PKU.

**For more information contact the Newborn Screening Program  
toll-free at 1-866-673-9939 or e-mail [NBS-Parent@michigan.gov](mailto:NBS-Parent@michigan.gov)**

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