

# Why Does My Baby Need More Testing for Galactosemia?



State law requires that all babies have the newborn screening test before leaving the hospital. A few drops of blood were taken from your baby's heel and tested for certain diseases. Your baby now needs more testing as soon as possible. Not all babies with an initial "positive" result will have galactosemia.

California  
Department of  
Health Services



Newborn Screening Program  
Genetic Disease Branch  
[www.dhs.ca.gov/gdb](http://www.dhs.ca.gov/gdb)

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## Why Does My Baby Need More Testing?

Your baby's test showed a "positive" result for galactosemia. More testing is needed to find out if your baby has this disease. Not all babies with an initial "positive" result will have this disease.

Babies can look healthy at birth and still have galactosemia. If untreated, this disease can cause severe health problems.

## What Is Galactosemia?

Galactosemia is a disease that causes galactose (a sugar in milk) to build up in the body. This buildup can damage the brain, eyes, liver and kidneys.

Babies with this disease are missing an enzyme called transferase, so they can't process galactose normally.

## How Does a Baby Get This Disease?

A baby with galactosemia inherited a gene from each parent. Both parents must carry the gene for a baby to inherit this disease.

## Is Galactosemia Common?

About one in 77,000 babies in California (about 7 babies a year) is born with this disease.

Other babies have milder forms of galactosemia. Babies with milder forms may not need treatment.

## What Should I Do Right Now?

- Stop breast milk or milk-based formula feedings as directed by the doctor.
- Return to the doctor's office or hospital lab as instructed for more testing for your baby.
- Feed your baby a soy-based formula while waiting for the result.



## What Symptoms Should I Look for?

Call the doctor if your baby:

- is not eating well
- has diarrhea or vomiting
- has yellow skin or eyes (jaundice)



## How Will I Know My Baby's Result?

The Newborn Screening staff reports the result to the doctor. The baby's doctor will let you know the results.

## What If the Test Is Negative?

Your baby does not have galactosemia. You can breastfeed or use a milk-based formula. Further testing is not needed.

## What If the Test Is Positive?

Keep feeding the soy-based formula. Your baby will be put on a galactose-restricted diet. The doctor will refer you to a metabolic clinic for treatment of your baby.

Foods containing milk and milk products cannot be eaten.



## How Is This Disease Treated?

Babies who test positive need formulas made with soy. Use **ONLY soy-based formulas** such as:

- Isomil®
- Prosoabee®
- I-Soyalac®
- Nursoy®



Babies who test positive **cannot** have breast milk or formulas made with milk.

**Do Not Use milk based formulas** such as:

- Similac®
- SMA®
- Enfamil®



When children with galactosemia start eating solid foods, they cannot have foods made with milk like yogurt, ice cream, or cheese. If you give your child these foods, she or he can get very sick.



## Where Can I Get More Information?

Call the doctor or the Newborn Screening staff listed below for any questions or concerns.

