

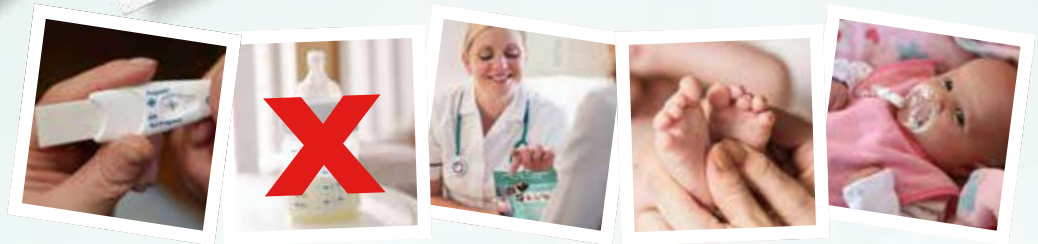
# Information for pregnant Traveller women

## Galactosaemia test during pregnancy



### Are you pregnant?

You can get a simple blood test when you're pregnant to see if your baby might have galactosaemia or not.



### What is Galactosaemia?

- Galactosaemia is a medical condition where the baby can get very sick from feeding on bottles of baby milk or breastmilk.
- A type of sugar found in this milk is very harmful to them.
- Babies with galactosaemia can only drink a special soy-milk.
- Galactosaemia is higher in Travellers.
- All Traveller babies have a heel prick test, called the Beutler test, as soon as they are born and are put on the special soy-milk until the results come back.
- The results will tell parents if their baby has to stay on the special soy-milk or not.
- Instead of waiting, Traveller women can get a test when they are pregnant that can let them know what milk the baby will go on when they are born.

### How do I get the test?

- Give this leaflet to your doctor or midwife/nurse at your appointment and ask them to read the back page.
- They will refer you and the baby's father to Crumlin Hospital (Genetics Department) for the test.
- The Genetics Department will get in touch with you to arrange an appointment and explain everything when you go in. They will refer you for a blood test which will be done by your doctor or in Crumlin Hospital.

### For more information

- Contact your Traveller Primary Health Care Worker
- Call the Pavee Mothers Programme, on **01 878 0255**
- Visit [www.paveemothers.ie](http://www.paveemothers.ie)

Hold your camera over the QR code to connect to the website



# Information for Medical Professionals



If you are a GP, practice nurse, midwife, maternity hospital doctor or other professional looking after a Traveller woman antenatally, this is information on how to refer for Classical Galactosaemia (CG) carrier status testing:

The Department of Clinical Genetics based in CHI Crumlin will fast-track carrier status testing for CG for pregnant Traveller women and their partners and explain the results to them.

Currently, newborn Traveller babies have a Beutler heel test immediately after birth to check for CG and cannot be fed breastmilk or baby formula until results are returned (between 1 and 3 days). Galactosaemia, an autosomal recessive gene, has a higher incidence in Travellers. When both parents carry the gene, there is a 1:4 risk of each of their babies having CG. If only one or neither parent carries the gene, the baby will not have CG and can be fed either breastmilk or baby formula and will not require a Beutler test at birth.

## How to refer for fast-track carrier status testing for Classical Galactosaemia:

- Referral is to the Department of Clinical Genetics in CHI Crumlin by a doctor only (GP or hospital doctor) as follows (both email and fax if possible):
  - Email: [clinical.genetics@olchc.ie](mailto:clinical.genetics@olchc.ie)
  - Fax: 01 456 0953
- Clearly highlight in the referral letter that the patient is a Traveller, is pregnant and therefore her baby is high risk for Galactosaemia. Mark the referral 'PREGNANT - URGENT' very clearly.
- Her appointment will be fast-tracked and she will be offered an appointment with a genetic counsellor in the Department of Clinical Genetics who will explain everything to her. The baby's father will also be offered a test at the same time.
- Please ensure that full contact details for the pregnant woman are included so that the Department of Clinical Genetics can make contact with her directly.

For more information contact the Pavee Mothers Programme.  
email: [info@pavee.ie](mailto:info@pavee.ie) or telephone: 01 878 0255