

QUESTIONS

If you have any questions, ask your grandchild's doctor.

For general newborn screening questions, call your state health department or the National Newborn Screening and Genetics Resource Center (NNSGRC) at 512-454-6419.



ADDITIONAL RESOURCES

1 . National Newborn Screening and Genetics Resource Center (NNSGRC)

<http://genes-r-us.uthscsa.edu>

2 . Health Resources and Services Maternal and Child Health Bureau

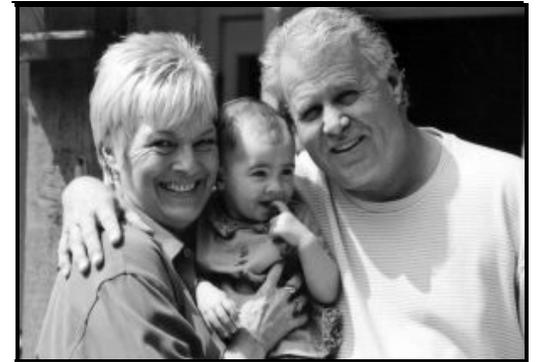
<http://mchb.hrsa.gov>

3 . March of Dimes

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

4 . Save Babies Through Screening

<http://www.savebabies.org>



Newborn Screening: A Guide for Grandparents

National Newborn Screening and Genetics Resource Center

1912 W Anderson Lane # 210

Austin, TX 78745

Phone (512)454-6419

Fax (512)454-6509

<http://genes-r-us.uthscsa.edu>



NEWBORN SCREENING:

TESTS THAT CAN SAVE A BABY'S LIFE

Newborn screening can save a baby's life or prevent brain damage. It is testing to find health problems shortly after birth so that they can be treated quickly.

1. Most babies are healthy when they are born.
2. All babies are tested because a few babies may look healthy, but are sick.
3. If problems are found early, serious problems like mental retardation and death can be prevented.

TESTING

1. Before your grandchild leaves the hospital, a few drops of blood will be taken from the baby's heel. This is the law.
2. The blood is put onto special paper and sent to a lab for testing.
3. This is a simple and safe process. Some babies sleep through it.



RESULTS

1. Screening results will be sent to your grandchild's doctor. This may take up to a week or slightly longer.
2. The doctor should notify the parents of the results. Parents should ask for them if they are not given.
3. When the results suggest a risk to the baby, the parents will be notified as soon as possible, and other tests will be done.
4. Results that suggest risk of a problem may not mean that there is a problem. Healthy babies may show increased risk for various reasons.
5. However, **ALL** babies with a positive screening result need other tests to learn if there really is a problem.
6. If your grandchild has a positive test, the parents will get a phone call or letter that tells them what to do next.

RESCREENING

1. Some babies may need rescreening. If rescreening is needed, the doctor or hospital will tell the parents.
2. Babies tested before 24 hours of age will probably need to be rescreened. In some states the time may differ.
3. Babies are required to be rescreened in some states. The doctor will know if this is a requirement.
4. Babies may need rescreening if there is a problem with the blood sample.
5. Babies with positive screening test results will require follow-up care. In some cases this may be a rescreen. In other cases it may mean an examination by a doctor and additional tests.

