

Office for Genetics and Children with Special Health Care Needs

Frequently Asked Questions

Newborn Screening

I just had a baby and would like to know how I get the results of my baby's newborn screening blood tests?

In most cases, you will not be personally notified if the test results are normal. Your doctor or clinic will get the report. Parents are usually notified only if there is a problem with one or more of the test results. Ask about the test results when you bring your baby to the doctor or clinic for a regular checkup. You can learn more about newborn screening by visiting the newborn bloodspot screening program website at:

http://www.fha.state.md.us/genetics/html/nbs_bloodspot.cfm

On this website, you can read or download 2 booklets about newborn screening. There is a video on newborn screening on the website:

http://www.fha.state.md.us/genetics/newborn_screening/Newborn_Screening.cfm

You can also call the office, 410-767-6736, for more information.

If your baby's results are not readily available at your doctor's office, you can call the newborn screening laboratory at 410-767-6099 and leave a message to send a duplicate report. You will need: baby's name as it was in the hospital, mother's full name, baby's date of birth, hospital in which the baby was born, your name and relation to the baby, the name of the baby's doctor and the name of the practice or doctor's office, the doctor's office phone number and fax number, and your phone number. HIPAA and State confidentiality laws require that we send the report to the baby's doctor. If there is an emergency, you or your baby's doctor can call the newborn screening follow-up program at 410-767-6736; explain the situation and a member of the follow-up team will help you at any hour of the day or night.

Does Maryland do "expanded newborn screening?"

Yes. Newborn screening is a rapidly growing service. The number of disorders included in the program has recently expanded from 9 disorders to 51 disorders. The "number" of disorders included is not a good way to judge the quality of a newborn screening program. Different programs count in different ways. It is more important to know that Maryland screens for all the disorders recommended by the March of Dimes and the American College of Medical Genetics.

Why is my permission required for newborn screening?

Most parents want to know what is important to their baby's health so they can be sure that their baby gets good care. Testing newborn babies for these disorders is an important part of good baby care. The Newborn Screening Program asks permission to do the testing in the same way that your baby's doctor asks permission to do any test on your baby. Maryland law requires that you be asked to give permission before metabolic

newborn screening tests are done. You will need to sign a permission form after your baby is born. Look over all the information you are given about newborn screening. Ask your OB doctor about newborn screening before your baby is born. You can watch the [video](#) or download the [brochure](#) from this website. Most hospitals have a video about newborn screening available. All hospitals have the brochures about newborn screening. Ask questions! This will give you the chance to say "yes" or "no." Please say, "YES!"

Sickle Cell Disease

What is Sickle Cell Disease?

Sickle Cell Disease is caused by an abnormal hemoglobin, hemoglobin S. A person with sickle cell disease has two abnormal genes (SS), one inherited from each parent. People with sickle cell disease have anemia, painful episodes and poor resistance to infections in childhood.

How can I avoid having a child with Sickle Cell Disease?

Both partners should be tested for their hemoglobin type before pregnancy. If both partners have sickle cell trait (AS), they have a 25% chance of having a baby with sickle cell disease and a 75% chance of having a baby who does not have sickle cell disease. They could choose other partners. They could hope for the good luck to be in the 75% (and prepare to care for a child with sickle cell disease if they are not lucky). They could have prenatal diagnosis to find out whether the baby has the disease and consider terminating the pregnancy if the baby does have SS. (Children with sickle cell disease do so much better now than they did 20 years ago, that very, very few couples choose to terminate the pregnancy.) Or they could adopt.

Is there any treatment or cure for Sickle Cell Disease?

The complications of sickle cell disease can be treated. Infections can be prevented with prophylactic penicillin and immunizations. Painful episodes can be minimized by avoiding extremes of hot and cold and staying well hydrated. There are drugs, principally hydroxyurea, that can reduce the number of painful episodes by about half. A painless test, the Transcranial Doppler test, can tell who is at high risk for a stroke by listening to the blood rush through blood vessels in the head. The chance of a stroke can be minimized, in high-risk patients, with regular blood transfusions. A few patients can tolerate bone marrow transplantation, and also have donors with the right tissue type. Bone marrow transplantation can effectively cure sickle cell disease, but is risky and expensive and most patients do not have matched donors (usually a brother or sister). For most patients, there is no cure only treatment. Treatment has been very successful in children identified through newborn screening and the death rate in young children has come down by almost a factor of 10 in the last 20 years.

What is Sickle Cell Trait?

A person with Sickle Cell Trait has one gene for the abnormal hemoglobin that causes sickle cell disease (S) and one gene for normal adult hemoglobin (A). Their hemoglobin type is AS. Individuals carrying one S gene are not sick. When two people with sickle cell trait (both AS) have a child, there is a 25% chance with each pregnancy that the baby will have sickle cell disease (SS), a 50% chance the baby will have sickle cell trait (AS), and a 25% chance the baby will have two normal genes (AA).

What should I do if I am already pregnant?

Both parents should be tested for hemoglobin type. If both parents have sickle cell trait (AS) then the baby can be tested. Prenatal diagnosis for sickle cell disease usually involves chorionic villus sampling (CVS) or amniocentesis. Both techniques collect a tiny bit of the baby's DNA for testing (from the membranes or from skin cells shed in the amniotic fluid). If the baby tests positive for sickle cell disease, the parents will need to decide if they want to proceed with the pregnancy. If the parents decide not to have prenatal diagnosis, the baby will be tested after birth in the newborn screening program.

Children's Medical Services (CMS)

What services does CMS pay for?

CMS pays for specialty care, including doctor visits, lab work, therapy, medical equipment, planned surgery, and medications.

Will the CMS Program pay for my child's emergency room visit (or admission)?

No. CMS does not pay for any emergency room visits or hospitalizations. If your child was seen in the ER and/or was admitted emergently, you can apply for emergency MA. You should also talk with the financial counselor at the hospital for assistance.

Does a child have to be a citizen or have a green card to apply to the CMS Program?

No, a child does not have to be a citizen or have a green card to apply to the CMS Program. However, the child must be able to document Maryland residency and qualify for financial eligibility.

How does my child qualify for the CMS Program?

To be eligible to apply for the CMS Program, you must show proof of the following: identity, residency, financial eligibility, medical eligibility, employment income and any other income, expenses, and insurance denial letter, if applicable. For more information on program qualifications, visit our website <http://www.fha.state.md.us/genetics/pdf/cmsapp.pdf> or call

410-767-5585 or 1-800-638-8864. The financial eligibility scale and the new medical deduction eligibility scale can both be found on our website at: <http://www.fha.state.md.us/genetics/html/elgib.cfm>.

How can I get a CMS application?

You can call our office at 410-767-5585 or 1-800-638-8864 and an application will be mailed to you, or visit our website at: <http://www.fha.state.md.us/genetics/pdf/cmsapp.pdf> to download a CMS application.

What happens after I complete the application?

Mail or bring the completed application to the Children's Medical Services Program, 201 W. Preston Street, Room 421 A, Baltimore, Maryland 21201.

What happens after I receive the CMS eligibility for services letter?

After you receive the CMS eligibility letter, contact your physician and/or specialist office to make an appointment. Call CMS at 410-767-5585 to tell them the name of your physician and/or specialist, appointment date, time, and location. For information on eligibility, call 410-767-5585 or 1-800-638-8864.

Specialty Care and Resource Development

How can I find resources for my child with special health care needs?

In Maryland, there are many State and local resources available to your child with special health care needs. Please visit the Office for Genetics and Children with Special Health Care Needs/Specialty Care & Regional Resources Development's website page at http://www.fha.state.md.us/genetics/html/region_resources.cfm for information regarding: Care Coordination, Outreach Specialty Clinics, Children's Medical Services, Health Care Transition, Linking Children and Youth with Special Health Care Needs and their Families to Services, Medical Home, The Parents' Place of Maryland, and much more. For additional information, please call the Office for Genetics and Children with Special Health Care Needs' Children's Resource Line at 1-800-638-8864 where knowledgeable staff can assist you.

Metabolic Nutrition

Does the State of Maryland pay for medical foods for people who have inherited metabolic disorders?

Maryland Medical Assistance pays for medical foods for patients who qualify financially. Information on how to apply for Medical Assistance is available from your local health department. Patients may also request payment for

medical foods from their private health insurance company. Maryland (House Bill 509, 1995) requires certain health insurance policies to provide coverage for medical foods.

How do patients in Maryland obtain Nutrition Services for inherited metabolic disorders?

Dietary management for certain inherited metabolic disorders is provided by the Maryland Department of Health and Mental Hygiene's Office for Genetics and Children with Special Health Care Needs and by several Genetics Centers in the State. Contact the Metabolic Nutrition Services Program at 410-767-6734 or 410-767-6735 for further information.

Infant Hearing

Why does my baby need to have a hearing test?

Hearing loss is the number one birth defect in the United States. One to three babies per 1000 a year will be born with a permanent hearing loss. It is important to find hearing loss as early as possible, because babies start learning how to use sound as soon as they are born. Early identification and early intervention are the keys to successful communication development. We know that if intervention starts by six months of age, children with hearing loss have the greatest chance of developing normal language and communication skills. This is why it is so important to have a newborn's hearing screened and follow up testing initiated as soon as possible. For additional information please call the Infant Hearing Program at 410-767-5803 or 1-800-633-1316. TTY 866-635-4410. Please visit our website at www.fhamd.org/infanthearing

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How do you test a baby's hearing?

There are two different types of hearing screening tests used to screen hearing in babies. Both of these tests are safe and comfortable for your baby.

Otoacoustic Emissions:

One of the tests is called otoacoustic emissions or OAEs. For this test, a miniature earphone and microphone are placed in the ear, sounds are played and a response is measured. If a baby hears normally, an emission is reflected back into the ear canal and measured by the microphone.

Auditory Brainstem Response

The second test is called the auditory brainstem response or ABR. For this test, sounds are played in the baby's ears. Band-aid like electrodes are placed on the baby's head to detect responses. This test measures how the hearing nerve responds to sounds and can identify babies who have a hearing loss.

Why should I have my baby's hearing retested if my baby responds to sound?

It is a good sign if you are noticing your baby is responding to sound. However, the only way to be sure that your baby is hearing normally is to have him tested. A baby who has a mild hearing loss or a loss in only one ear will respond to sound, but these types of losses can lead to difficulties with speech and language development. They can also create safety issues you need to be aware of. Additionally, as the baby gets older, this type of loss can cause the child to appear to have behavioral problems. All of these problems can be avoided or minimized if the baby gets appropriate timely intervention. To be most effective, intervention needs to begin before six months of age.

Where can I go to have my baby's hearing tested?

Often, the second hearing screening can be done on a return visit to the birth hospital. If not, or if your baby needs a full hearing evaluation, your pediatrician can refer you to an audiologist or contact the Infant Hearing Program for additional information. If you have concerns about your baby's hearing don't delay. Have your child's hearing tested by an audiologist as soon as possible. A child's hearing can be tested at any age. Remember, early identification and intervention is the key to successful communication development.

Birth Defects Reporting and Information System

What is The Birth Defects Reporting and Information System?

Maryland law established the BDRIS in 1982. Data collection began September 1, 1983. This system has historically collected data on the number of babies born with any of twelve common birth defects, monitored birth defect trends especially in relationship to environmental hazards, and provided information on the defects and services to the parents and families of affected infants. All patients with these disorders are eligible for information and referral services at no charge. The twelve "sentinel" birth defects are chosen by the World Health Organization for their international birth defects surveillance program. These include: Anencephaly, Spina Bifida, Hydrocephalus, Cleft Lip with or without Cleft Palate, Cleft Palate, Esophageal Atresia/Tracheo-Esophageal, Fistula, Rectal/Anal Atresia, Hypospadias, Reduction Deformity (upper limb), Reduction Deformity (lower limb), Congenital Hip Dislocation, and Down Syndrome. In 2008 legislation was passed to expand the program to collect data on all significant birth defects.

Language Interpretation

How do patients who do not speak English get services?

Interpreters are available upon request for non-English speaking patients and their families.