

Office for Genetics and People with Special Health Care Needs Frequently Asked Questions

Children with Special Health Care Needs and Title V

Who are children with special health care needs (CYSHCN)?

Children and youth with special health care needs are defined by the national Maternal Child Health Bureau as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." That being said, CYSHCN are kids; kids who also happen to need extra care. They are kids with Downs Syndrome, with ADHD, with asthma, with cerebral palsy, with autism, with bipolar disorder, with anxiety, with undiagnosed disorders, with congenital birth anomalies, and lots of other disorders. They are kids who love to play and do anything else typical kids do. CYSHCN are of all ethnicities, races, economic status, gender, family structure and live in all communities. In Maryland, almost one in six children have a special health care need, and almost 1 in 4 households with children have at least one CYSHCN.

What is Title V and what does it have to do with children with special health care needs (CYSHCN)?

Title V refers to Title V of the Social Security Act. Since 1935, this federal legislation allows for specific MCH programs to provide a base to build upon, with the goal of improving the health of all women, children, youth, and families; Title V remains the only Federal program with this broad of a mandate. Its purpose is to Improve the health of all mothers and children in the Nation and serves 3 distinct population groups: Pregnant women, mothers and infants; Children and Adolescents; and Children and Youth with Special Health Care Needs (CYSHCN).

Major goals of Title V Program for CYSHCN are: to provide and ensure access to comprehensive health care, including long-term care services, for CYSHCN and to facilitate the development of family-centered, community-based, and culturally competent comprehensive care for CYSHCN and their families.

Title V funds are given to states in a "block grant" - this is a formula grant where the amount given to states is determined by the percentage of low income children in a State. Funds can be used by states to design and implement a wide range of maternal and child health programs that meet national and State needs, and States have a large degree of flexibility in determining priorities and allocating Federal funds in order to address the needs of their populations more appropriately.

For more information on the federal Title V Program, visit:
<http://mchb.hrsa.gov/programs/titlevgrants/index.html>

The Office for Genetics and People with Special Health Care Needs is Maryland's Title V CYSHCN program. OGPSHCN's priorities include the 6 core outcomes for CYSHCN (which are national and state priorities):

- Families of CYSHCN partner in decision making at all levels and are satisfied with the services they receive (to learn more visit <http://www.fv-ncfpp.org>);
- CYSHCN receive coordinated ongoing comprehensive care within a medical home (to learn more visit <http://www.medicalhomeinfo.org>);
- Families of CYSHCN have adequate private and/or public insurance to pay for the services they need (to learn more visit <http://hdwg.org/catalyst>);
- Children are screened early and continuously for special health care needs;

- Community-based services for CYSHCN are organized so families can use them easily (to learn more visit <http://www.communitybasedservices.org>);
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence (to learn more visit <http://www.gottransition.org>.)

OGPSHCN and a broad group of stakeholders also identified 3 state priorities for Maryland's approximately 244,000 CYSHCN:

- **Improve Data Systems and Sharing:** Improve state and local capacity to collect, analyze, share, translate and disseminate maternal and child health data and evaluate programs.
- **Strategic Partnerships:** Sustain, strengthen and maximize strategic partnerships through the Community of Care Consortium to address CYSHCN core outcomes in Maryland.
- **Healthy and Productive Youth and Young Adults (Transition to Adulthood):** Improve supports for the successful transition of all youth to adulthood

Grants

Does the Office for Genetics and People with Special Health Care Needs (OGPSHCN) provide grants and other types of funding to organizations to address the needs of CYSHCN?

The OGPSHCN's Infrastructure and Systems Development Unit, is the focal point for the development of programs and services for CYSHCN. OGPSHCN's mission is to assure a comprehensive, coordinated system of care that meets the needs of Maryland's CYSHCN and their families and is community-based, family-centered and culturally competent. Systems Development Grants funds projects that contribute to the improvement of Maryland's system of care for CYSHCN by addressing the

OGPSHCN System of Care Shared Goals, which include the six core outcomes, disparities (region of residence within state, socioeconomic status, race/ethnicity, primary language spoken at home, and severity or complexity of condition); and system of care characteristics (community-based, coordinated, family-centered, and culturally competent). Systems development grants are awarded on an annual basis. When there is an active Call for Proposals, it is available on the OGPSHCN website.

Newborn Metabolic Screening

What is Newborn Metabolic Screening?

The Newborn Metabolic Screen is a special test used to screen your baby for over 50 serious medical conditions. The goal of the screen is to identify babies who have these disorders before they ever get sick, and to help them get treatment as soon as possible. This test is sometimes referred to as the "PKU" test (an older term), by the medical community.

How is the Newborn Metabolic Screen performed?

The Newborn Metabolic Screen is performed by pricking your baby's heel and putting a few drops of blood onto special paper called filter paper. The filter paper is allowed to dry and is then sent to the State Health department. Once the blood gets to the Health Department, it is analyzed by the lab to identify babies who are at higher risk to have a medical condition. If the screen indicates your baby might have a medical problem, a member of the newborn screening follow-up team will call your baby's

doctor with the results. If we cannot identify the baby's doctor, we may call you directly to get this information.

Should all babies born in Maryland get the test?

Yes! All babies born in the state of Maryland should get a Newborn Metabolic Screening test. Most babies get their first screen at the hospital and their second at the pediatrician's office. If you choose to deliver your baby at home it is important to talk to your pediatrician or family doctor about your baby having the Newborn Metabolic Screen as soon as possible

Do I get to see my baby's results?

We do not send the results directly to parents. However, you should talk to your baby's doctor and make sure he/she has a copy of the results. You can ask the baby's doctor to give you a copy of the results.

What happens if my baby has a positive test?

If your baby has a positive test result, we attempt to contact the baby's pediatrician or primary care doctor. We find out the doctor's information and your baby's name from the form connected to the blood spot that was filled out when the baby was in the nursery. It is important to make sure the birth facility has your most accurate contact information so that we can reach you easily if there is a problem. If we do not know who the baby's doctor is, we will call you directly to find out this information. If you do not have a working number listed we will send a certified letter to your address.

Does a positive test mean my baby has the condition?

No. Sometimes the result will be what we call a "false positive". This means that the baby's initial results showed that they were at a higher risk to have the disorder, but the follow-up testing was normal. Other times the result does indicate the baby has a real problem.

Newborn screening is only a "screening" test, it is not a "diagnostic" test. This means that the test was made to find babies who may have a medical problem. If a baby has a positive screening test, he/she should get the recommended follow-up testing. This testing may be done by your baby's doctor or another specialist. The newborn screening follow-up team will help facilitate this testing.

What if my baby looks healthy?

Most babies who have these conditions look healthy and act normally in the newborn period. The point of the test is to try to find babies that have these problems before they get sick. Just because your baby looks healthy does not mean he/she is healthy and it is important to listen to your doctor's advice.

Critical Congenital Heart Disease Screening

What is Critical Congenital Heart Disease?

Critical Congenital Heart Disease is defined as a heart defect that is present at birth and can cause serious illness or even death if not detected in the first few weeks of life.

What Causes Critical Congenital Heart Disease?

The actual cause is not known. However, it is known that certain environmental and genetic risk factors can increase the risk of abnormalities in the development of a baby's heart:

1. Drinking alcohol regularly during pregnancy
2. Maternal diabetes
3. Mother's age (over 40)
4. Poor nutrition during pregnancy
5. Rubella or other viral illnesses during pregnancy
6. Chromosomal (genetic) disorders such as Down Syndrome or DiGeorge Syndrome

How is Critical Congenital Heart Disease detected?

Sometimes critical congenital heart disease can be detected prenatally on a sonogram or during your baby's first physical exam. However, many babies can appear healthy in the first few days which makes pulse oximetry screening important.

What is Pulse Oximetry Screening?

Pulse Oximetry Screening is a painless test that detects the oxygen level in your baby's blood. The level of oxygen needs to be checked in the right hand and either the right or left foot.

When is the Pulse Oximetry screening performed?

The screening is performed between 24-48 hours after birth.

How is the Pulse Oximetry Screening Performed?

A soft sensor is wrapped around the baby's right hand and one of the feet using a sticky strip like a band aid. The sensor uses a light to detect the oxygen level of the baby's blood.

What happens if the results are abnormal?

Your baby's doctor will order additional tests to find out why the oxygen level is low. These tests should be conducted before your baby leaves the hospital. The best test to determine if a baby has Critical Congenital Heart Disease is an echocardiogram, which is an ultrasound of the heart.

Can Pulse Oximetry Screening detect all congenital heart defects?

Unfortunately, not all congenital heart defects can be detected at birth but some types of critical congenital heart defects can be detected most of the time using by the pulse oximetry screening combined with the newborn physical exam. The seven CCHD defects targeted by pulse oximetry screening are:

- [Hypoplastic Left Heart Syndrome](#)
- [Pulmonary Atresia](#)
- [Tetralogy of Fallot](#)
- [Total Anomalous Pulmonary Venous Return](#)
- [Transposition of The Great Arteries](#)
- [Tricuspid Atresia](#)
- [Truncus Arteriosus](#)

It is important to remember that pulse oximetry screening may not detect these defects 100% of the time, and it may also pick up other heart defects or illnesses in the infant.

What is the treatment for Critical Congenital Heart disease?

Medication can be used temporarily but surgery is typically needed to correct blood flow.

What are the signs/symptoms of Critical Congenital Heart Disease?

Blush skin color, especially around the lips and fingernails
Delayed growth and development
Poor feeding and poor growth
Fast and difficult breathing
Lethargy (tiredness)

If your baby has any of these symptoms, even if he or she has "passed" the pulse oximetry screening, notify your baby's doctor immediately.

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 know if my child will have 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. Genetic counseling is strongly recommended for these families. They could also have prenatal diagnosis to find out whether the baby has sickle cell disease.

Is there any treatment or cure for Sickle Cell Disease?

The complications of sickle cell disease can be treated. Infections can be prevented with daily penicillin and immunizations. Painful episodes can be minimized by avoiding extremes of hot and cold and staying well hydrated. There are drugs, like 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, if they have donors with the right tissue type. Bone marrow transplantation can effectively cure sickle cell disease, but it 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 for services related to a chronic illness/disabling condition, including doctor visits, lab work, radiology services, therapy, medical equipment and supplies, 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, emergency admissions or sick visits to a physician or urgent care center. If your child was seen in the ER and/or was admitted emergently, you may be eligible to 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 meet other eligibility criteria.

How does my child qualify for the CMS Program?

A completed, signed and dated CMS Program application must be mailed to the CMS Program office along with all requested supporting documentation, including: proof of identity, proof of Maryland residency, proof of income, and documentation of a chronic/disabling medical condition. For more information on program qualifications, visit our website:

http://phpa.dhmh.maryland.gov/genetics/SitePages/CMS_Program.aspx or call 410-767-5588 or 1-800-638-8864.

How can I get a CMS application?

You can call our office at 410-767-5588 or 1-800-638-8864 to request an application to be mailed to you, or visit our website at:

<http://fha.dhmh.maryland.gov/genetics/SitePages/specialcare.aspx> to download a CMS application.

What happens after I complete the application?

Mail the completed application with all requested documentation to the Children's Medical Services Program, 201 W. Preston Street, Room 423, Baltimore, Maryland 21201. CMS has 30 days to process the complete application. You will be notified by mail of eligibility approval or denial.

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

After you receive the CMS eligibility letter, you will be contacted by the care coordinator listed in your letter. The care coordinator will advise you of your eligibility and other important information about the program. The care coordinator will also assist you in making the initial appointment with the specialist.

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 for your child or youth with special health care needs. Please visit the Office for Genetics and People with Special Health Care Needs' Resource Locator for CYSHCN at <http://specialneeds.dhmh.maryland.gov/>

This is an easy to use online database designed to help families of children with special health care needs, youth and providers find needed resources. It is accessible in over 50 languages, and offers user-friendly features including helpful search features, interactive maps and directions to each resource, and is 508-compliant for those with visual impairments.

For additional information, please call the Office for Genetics and People 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. The metabolic nutritionist caring for a patient often has information on how to obtain special foods.

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 1-800-633-1316. TTY 866-635-4410. Please visit our website at http://phpa.dhmdh.maryland.gov/genetics/SitePages/Infant_Hearing_Program.aspx

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 speech and language

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.

Is personal information about me or my baby given to the CDC?

No. The reports given to the CDC contain only numbers. We report how many infants are born each year in Maryland with particular 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.