Chapter 4 : Newborn Screening

Almost every child born in the United States undergoes state-mandated newborn screening. For each state, a small blood sample ("heel stick") is collected from each newborn within 48 hours of birth and sent to a laboratory for testing for a panel of genetic disorders. Newborn screening programs may screen for up to 50 diseases, including phenylketonuria (PKU), sickle cell disease, and hypothyroidism. About 3,000 newborns test positive each year for one of these severe disorders. In the event that a newborn screens positive for one of the disorders, screening allows early intervention that can lead to significant reduction in disease severity and possibly even prevention of the disease. This chapter provides an overview of newborn screening programs and the specific conditions and procedures for the District of Columbia, Virginia, and Maryland.

Newborn screening is the first public health program for genetic conditions. In the U.S., newborn screening programs are state-mandated and the diseases screened in each state may vary. Efforts are underway to develop a national newborn screening program. New technologies have enabled substantial expansion of newborn screening programs.

4.1 Overview of Newborn Screening

Each year, more than 95% of all children born in the United States (at least 4 million babies) are tested for a panel of diseases that, when detected and treated early, can lead to significant reduction in disease severity and possibly even prevention of the disease. About 3,000 newborns test positive for one of these severe disorders.

Within 48 hours of a child's birth, a sample of blood is obtained from a "heel stick," and the blood is analyzed for up to 50 diseases, including phenylketonuria (PKU), sickle cell disease, and hypothyroidism. The sample, called a "blood spot," is tested at a state public health or other participating laboratory.

4.2 Newborn Screening Programs

Since newborn screening is a state-operated program, each state differs slightly in which diseases are included in newborn screening programs depending on disease prevalence, detectability, treatment availability, outcome, and overall cost effectiveness. Typically, each state has an advisory committee that reviews and selects which diseases are screened for based on current scientific and clinical data. Increasingly, tandem mass spectrometry is being used for newborn screening of up to 50 additional metabolic disorders from dried blood-spot specimens. A recent report commissioned by the US Health Resources and Services Administration recommended uniform screening for 29 genetic diseases. Efforts are underway to examine the feasibility of instituting uniform newborn screening policies.

4.2.1 District of Columbia. Since 1980, the mission of the District of Columbia Newborn Screening Program is to detect, diagnose, and treat every newborn baby who tests positive for certain inherited genetic disorders. This program can mean the difference between life and death for a newborn. It can also prevent life-threatening complications and serious chronic consequences such as mental retardation, developmental disability, liver disease, blindness, neurological degeneration, malnutrition, and death.

The vision of the Newborn Metabolic Screening Program in the District of Columbia is that all newborns are screened for metabolic disorders prior to hospital discharge. The Program's purpose is to require all hospitals in the District of Columbia to screen for 40 inherited genetic disorders that are treatable by diet, vitamins and/or medication, or by anticipatory measures to prevent attacks.

The overall goal of the Program is to ensure that every infant born in the District is screened for 40 inherited genetic disorders and that infants identified with abnormal screening results receive timely and appropriate follow-up, to treat inherited diseases before the onset of clinical symptoms.

Program Objectives:

- To assure that all infants born in the District of Columbia are screened and that testing is processed within 5 days of birth.
- To assure that all families and affected infants receive timely and appropriate confirmatory testing, counseling, and treatment.
- To assure that all newborns diagnosed with a metabolic disease or hemoglobin abnormality are entered into and maintained on appropriate medical therapy.

4.2.1.1 Disorders Screened. Final rulemaking to amend DC Law 3-65 was published and made effective on November 4, 2005. The amendment expands the current panel of newborn screening disorders in the District of Columbia from seven to 40 disorders. The expanded panel includes screens for inherited hemoglobinopathies and 39 metabolic disorders. Every infant born in a District of Columbia hospital and birthing center will be screened for the following disorders. See the consumer fact sheet on newborn screening for a brief description of the diseases.

1. 2,4-Dienoyl-CoA reductase deficiency
2. 2-Methylbutryl-CoA dehydrogenase deficiency
3. 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
4. 3-Methylglutaconyl-CoA hydratase deficiency
5. 3-OH 3-CH3 glutaric aciduria or 3-hydroxy-3-methylglutaryl-CoA lyase deficiency (HMG)
6. 5-Oxoprolinuria (pyroglutamic aciduria)
7. Argininemia
8. Argininosuccinic acidemia (ASA)
9. Beta-ketothiolase deficiency (BKT)
10. Biotinidase deficiency (BIOT)
11. Carbamoylphosphate synthetase deficiency (CPS def.)
12. Carnitine uptake defect (CUD)
13. Citrullinemia (CITR)
14. Congenital adrenal hyperplasia (CAH)
15. Congenital hypothyroidism
16. Cystic fibrosis (CF)
17. Galactosemia
18. Glucose-6-Phosphate dehydrogenase deficiency (G6PD)
19. Glutaric acidemia type I (GA-I)
20. Hemoglobinopathy
21. Homocystinuria
22. Hyperammonemia, hyperornithinemia, homocitrullinemia syndrome (HHH)
23. Hyperornithine with gyrate deficiency
24. Isobutyryl-CoA dehydrogenase deficiency
25. Isovaleric acidemia (IVA)
26. Long-chain L-3-OH acyl-CoA dehydrogenase deficiency (LCHADD)
27. Malonic aciduria

28. Maple syrup urine disease (MSUD)
29. Medium chain acyl-CoA dehydrogenase deficiency (MCADD)
30. Methylmalonic acidemia
31. Multiple acyl-CoA dehydrogenase deficiency (MADD)
32. Multiple carboxylase deficiency (MCD)
33. Neonatal carnitine palmitoyl transferase deficiency-type II (CPT-II)
34. Phenylketonuria (PKU)
35. Propionic acidemia (PROP)
36. Short chain acyl-CoA dehydrogenase deficiency (SCAD)
37. Short chain hydroxy acyl-CoA dehydrogenase deficiency (SCHAD)
38. Trifunctional protein deficiency (TFP)
39. Tyrosinemia type I (TYRO-I)
40. Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

4.2.1.2 Procedures and Follow-Up. Every live born infant shall have an adequate blood test for all disorders defined in the District of Columbia Newborn Screening Requirement Act upon informed consent by the parent. The initial screening is to be done in the hospital and may be repeated, as necessary, prior to discharge. When a live birth occurs in a hospital or birthing center, the physician shall have a blood specimen by filter paper of the infant's blood taken prior to the infant's discharge from the hospital or birthing center. The infant's blood for these tests shall be collected not earlier than 24 hours after the first feeding following birth and no later than when the infant is one week old. If the infant born in a hospital or birthing center is discharged before 48 hours after birth, a blood specimen shall be collected prior to discharge. In this case, the newborn must be tested again prior to one week of age. The hospital or birthing center should provide written notice of this requirement to the parents, guardian, or other legally responsible person.

The hospital or birthing center must inform the parent about the purpose of testing and must document in the newborn's health record that the parent was educated about the test and that the parent gave consent or non-consent to test. Each specimen is forwarded to a single laboratory designated by the Mayor, in accordance with the DC Newborn Screening Law. The blood sample and the required patient information must be sent to the approved laboratory on the day of collection for an adequate test.

The laboratory performing blood tests for the purpose of satisfying legal requirements for testing newborns shall report all such test results to the hospital where the birth occurred. The results shall be part of the infant's medical record. The laboratory shall report all results to the Department of Health, Maternal and Family Health Administration, Children with Special Health Needs Division's Metabolic Screening Program on the day testing is completed of all positive and inconclusive test results and this report shall include the patient's required information.

The Children with Special Health Needs (CSHCN) Newborn Metabolic Screening Program notifies the infant's parent(s) and the newborn's physician about abnormal findings, and assists in securing appropriate follow-up testing and treatment when indicated. CSHCN refers critical infants to specialists within the District of Columbia that offer evaluation, treatment and counseling services. Specialty centers for endocrinology, hematology, and medical genetics are located throughout the District of Columbia. For newborns with presumptive positive results (except for G6PD and Sickle Cell Trait), the following steps should be taken by

CSHCN to notify parents/guardians and follow-up with confirmation of the screening result and intervention as needed:

- Notify newborn's parent(s)/guardian by telephone within 24-48 hours following receipt of abnormal screen result from the laboratory.
- Recommend immediate pediatric/primary physician/clinic appointment.
- Recommend immediate evaluation by a Specialty Treatment Center.
- Recommend family testing and counseling.
  - Verify infant's demographic information.
  - Obtain name, telephone number, and address of the infant's physician.
  - Assist with scheduling physician appointment.
  - If there is no designated physician, seek a physician or refer the infant directly to a Special Treatment Center.
  - If mother's telephone number is disconnected or incorrect, call the birthing hospital/maternity center to verify the telephone number or request telephone numbers of other family members to contact.
  - If unable to locate and DC address is located in Ward 5, 6, 7, or 8, request DC Healthy Start to make a home visit. For other DC Wards, contact DC Medicaid to obtain additional information.
  - If unable to locate and residence is in Maryland or Virginia, contact MD or VA Newborn Screening Program for assistance.
  - Document each telephone contact with family, including name of contact persons, address, telephone number, date, and time. Enter information into DC Newborn Screening case management information system (in development).
    - Send Parent Letter and disorder fact sheet by mail. Document mailing date.
    - Follow-up with mother/physician to assure that doctor appointments are kept. If doctor appointments have not been kept, assist the parent in scheduling and maintaining appointments. If after counseling the parent on the impact of lack of follow-up care and the parent still fails to comply, referral to Child Protective Services should be made.
  - Notify newborn's pediatric/primary care physician by telephone within 24-48 hours following receipt of abnormal screening result from the laboratory.
  - Recommend immediate pediatric/primary care physician appointment
  - Recommend immediate evaluation by specialty treatment center.
  - Recommend family testing and counseling.
  - If physician is unavailable, report all information to office/clinic nurse.
  - Assist with scheduling physician appointment for infant and report back to mother by telephone.
  - Obtain name of preferred Specialty Treatment Center. Fax Specialty Treatment Center Referral form to the Specialist, if necessary.

- Fax Pediatrix Screening Test Result Report, Physician Letter, Physician Alert, and List of Specialty Centers. Request that test results and supporting information are included in the infant's medical record.
- Document each telephone contact with physician/nurse, including name, address, telephone number, date and time, and Fax date. Enter information into the DC Newborn Screening case management information system.
- Contact the Specialty Treatment Center within two weeks for follow-up.
- Obtain final diagnosis, name of treatment, and treatment start date. Enter information into DC Newborn Screening case management information system.
- For non-compliant family, contact infant's parents and physician, social worker, outreach worker, or other medical, social, or financial personnel as appropriate.

For newborns screening positive for Sickle Cell Trait and G6PD, the following steps should be taken to notify parents/guardians and follow-up with confirmation of the screening result and intervention as needed:

- Refer infant for follow-up testing and counseling.
- Notify the newborn's parents by mail within 48 hours following receipt of screening result from the laboratory.
- For those with Sickle Cell Trait, mailing includes Parent Letter and Sickle Cell Trait fact sheet.
- For those with G6PD, mailing includes parent letter, parent alert, physician alert, and G6PD fact sheet.
- Recommend confirmatory testing of infant. Infants with G6PD should be retested between six and 12 months of age.
- Recommend parent testing and counseling by family physician and genetic counselor.

In the event that unacceptable results are returned, the following steps should be taken to notify the parents/guardians and re-schedule a second screening:

- The laboratory contacts the submitting hospital to request a repeat screen. The submitting hospital is responsible for repeating unacceptable samples.
- The laboratory notifies the CSHCN of the unacceptable result.
- The submitting hospital is responsible for contacting the newborn's parent(s) to arrange for a repeat/second screen.
- The submitting hospital shall submit a second screen to the laboratory before the infant is one week old.
- CSHCN will notify the newborn's parent(s) by mail within 48 hours following receipt of the unacceptable screening result from the laboratory.
- CSHCN will follow-up with the infant's parent(s), hospital and/or laboratory within one week to confirm repeat screen and obtain results.

For more information on the DC Newborn Screening Program, contact the DC Department of Health at (202) 671-5000.

4.2.1.3 Universal Newborn Hearing Screening. All infants born in the District of Columbia are required by law to be screened at birth for hearing loss. The DC Hears program works for early detection of hearing loss and provides services for all children from birth to five years of age who have been diagnosed with hearing loss or deafness, regardless of their level of income. DC Hears provides free hearing screening and loaner amplification to all DC children in need of services. If hearing loss is not discovered early, the child could experience delays in speech, language, emotional, and educational development.

There are two tests for screening newborn hearing: OAE (otoacoustic emissions) and ABR (auditory brainstem response). A baby may be given one or both of these tests. In the OAE test, a soft rubber earpiece is placed in the baby's ear canal to deliver a soft sound. This test measures how well the baby's inner ear responds to sound. In the ABR test, earphones are placed over the baby's ear canal to deliver sound. This test measures how the brain responds to sounds. Typically, testing is done when the baby is asleep and not aware of the testing. Results are available immediately after testing.

Passing the hearing screening indicates that the baby's hearing is within the normal range at the time of the test. However, some babies with a family history of hearing loss, repeated ear infections, or serious illness may develop hearing loss later. The child's hearing and speech should be monitored as he or she grows.

Not passing the hearing screening indicates that the baby should have a second hearing test. The second screening should occur while the baby is still in the hospital or within two weeks after leaving the hospital. If the baby does not pass the initial hearing screening, it does not mean that the baby has permanent hearing loss since most babies pass the second screening. Often babies can have fluid, blockage, or debris in the ear that clears up on its own. If further testing shows that a baby has hearing loss, an audiologist along with an ear/nose/throat specialist can best determine the next steps. Treatment will depend on the type and degree of hearing loss. If hearing loss is permanent, hearing aids or special services may be recommended. Infants can be fitted with a hearing aid as young as one month of age.

4.2.2 Virginia. The Pediatric Screening and Genetics Services, a unit within the Division of Child and Adolescent Health, Virginia Department of Health administers the Virginia Genetics Program and the Virginia Early Hearing and Intervention Program. Newborn screening is offered to families with new babies as a service through the Virginia Department of Health.

4.2.2.1 Disorders Screened. All infants less than six months of age who are born in Virginia are currently screened for a number of genetic disorders. Any infant whose parent or guardian objects on the grounds that the tests conflict with his religious practices or tenets will not be required to receive screening.

Effective March 2006, the number of genetic diseases screened is 28, utilizing both traditional laboratory and tandem mass spectrometry (MS/MS) methods.

1. 3-hydroxy 3-methyl glutaric aciduria (HMG)
2. 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
3. Argininosuccinic acidemia (ASA)
4. Beta-Ketothiolase deficiency (ßKT)
5. Biotinidase deficiency (BIOT)
6. Carnitine uptake defect (CUD)
7. Citrullinemia (CIT)
8. Congenital adrenal hyperplasia (CAH)
9. Congenital hypothyroidism (CH)
10. Cystic fibrosis (CF)
11. Galactosemia (GALT)
12. Glutaric acidemia type I (GA I)
13. Hemoglobin Sickle/Beta-thalassemia (Hb S/ßTh)
14. Hemoglobin Sickle/C disease (Hb S/C)
15. Homocystinuria (HCY)
16. Isovaleric acidemia (IVA)
17. Long chain hydroxyacyl-CoA dehydrogenase deficiency (LCHAD)
18. Maple syrup urine disease (MSUD)
19. Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
20. Methylmalonic acidemia (mutase deficiency) (MUT)
21. Methylmalonic acidemia (Cbl A, B)
22. Multiple carboxylase deficiency (MCD)
23. Phenylketonuria (PKU)
24. Propionic acidemia (PROP)
25. Sickle cell anemia (Hb SS disease)
26. Trifunctional protein deficiency
27. Tyrosinemia type I (TYR I);
28. Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

4.2.2.2 Procedures and Follow-up. The initial screening tests are performed by the Virginia Department of General Services, Division of Consolidated Laboratories Services (DCLS). Currently, it takes three days to process and complete screening on a routine sample. DCLS also performs repeat tests on infants up to six months of age. A second routine newborn screening test is not mandated in Virginia because it is costly and has not been shown to yield an increase in the number of cases. A second screen is required only when an abnormal test result occurs or when a sample has been collected when the infant is less than 24 hours of age.

Results are mailed back to the submitter (usually the hospital of birth) and the primary health care provider listed on the filter paper device for all newborn screening tests. In addition, the health care provider/physician listed on the filter paper device is also notified by telephone within 24 hours regarding all critically abnormal results.

Questions regarding the interpretation of results should be directed to the Virginia Department of General Services, DCLS, Newborn Screening Section at (804) 648-4480 ext. 170. Questions regarding procedures for follow-up should be directed to the Newborn Screening Nurse, Pediatric Screening and Genetic Services, Division of Child and Adolescent Health, Virginia Department of Health at (804) 864-7714 or (804) 864-7715.

The Virginia Department of Health has retained the services of metabolic, medical and endocrinology consultants to provide assistance with test interpretation, diagnostic testing, and treatment of affected infants. There are four Regional Genetic Centers that provide genetic testing, counseling, and education for all residents, especially those with very limited resources.

Virginia Commonwealth University Health System
Medical College of Virginia Hospitals
Genetics Program
P.O. Box 980033
Richmond, Virginia 23298

Eastern Virginia Medical School
Department of Pediatrics
Division of Medical Genetics
601 Children's Lane
Norfolk, Virginia 23507-1921

University of Virginia
Division of Medical Genetics
Department of Pediatrics
Box 386
Charlottesville, Virginia 22908

Fairfax Genetics & IVF Institute
Genetics Program
3020 Javier Road
Fairfax, Virginia 22031

In addition, two metabolic treatment programs are available for children identified through the Newborn Screening Program and provision of food products for management of PKU. Metabolic treatment procedures are recommended and such treatment is provided for infants in medically indigent families by the following health-care providers. The health-care providers offer physician and nutrition consultation.

University of Virginia
Division of Medical Genetics
Department of Pediatrics
www@virginia.edu

Virginia Commonwealth University
Medical College of Virginia Campus
School of Medicine
Department of Pediatrics
lduncan@hsc.vcu.edu

For more information on the Virginia Newborn Screening Program, see *http://www.vahealth.org/genetics/servgp.htm#newbornscreening.*

In addition, providers should consult the following web-site for answers to frequently asked questions: *http://www.vahealth.org/genetics/Newborn%20Screening%20Facts_404.pdf.*

4.2.2.3 Universal Newborn Hearing Screening. The Code of Virginia requires that all hospitals with newborn nurseries and all hospitals with neonatal intensive care services will screen the hearing of all newborns prior to discharge and report to the Virginia Department of Health. Hospitals are also required to inform the parent and the child's primary health care provider about the infant's risk status and/or screening results and recommendations for follow-up. Persons who provide audiological services are required to: 1) report children who are at risk for hearing loss, children who fail to pass a hearing screening, and children identified with hearing loss to the Virginia Department of Health; and, 2) to give parents information about hearing loss, including choices about learning communication, and to refer them to local early intervention services.

For more information, see *http://www.vahealth.org/hearing/index.htm*

4.2.3 Maryland. All Maryland residents are eligible for newborn screening services. Clinical services are charged on the sliding fee scale with all types of third party payment accepted and no patient is refused service for inability to pay. The Maryland Department of Health and Mental Hygiene's laboratory charges a nominal fee to analyze newborn screening specimens. (The charge is currently $42 per child and covers as many screening specimens as may be needed.) The Department of Health and Mental Hygiene determines whether specimens are satisfactory and which tests shall be employed.

4.2.3.1 Disorders Screened. This program identifies and follows-up on newborn babies with any one of 32 rare and serious disorders of body chemistry. Maryland implemented expanded screening using tandem mass spectrometry in November 2003. Cystic fibrosis will be added in the near future. Testing is performed at either the State Public Health Laboratory or the commercial laboratory Pediatrix.

1. 2-Methylbutyryl-CoA Dehydrogenase Deficiency
2. 3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency (HMG CoA Lyase Deficiency)
3. 3-Methylcrotonyl-CoA Carboxylase Deficiency (3MCC Deficiency)
4. 3-Methylglutaconyl-CoA Hydratase Deficiency
5. Argininosuccinic aciduria
6. Argininemia/Citrullinemia
7. Biotinidase deficiency
8. Carnitine/Acylcarnitine Translocase Deficiency
9. Carnitine Palmitoyl Transferase II Deficiency (CPT II Deficiency)
10. Congenital Adrenal Hyperplasia
11. Galactosemia
12. Glutaric Acidemia Type I
13. Homocystinuria
14. Hypothyroidism
15. Isobutyryl-CoA Dehydrogenase Deficiency
16. Isovaleric Acidemia
17. Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)
18. Maple Syrup Urine Disease (MSUD)
19. Medium Chain Acyl –CoA Dehydrogenase Deficiency (MCAD)
20. Methylmalonic Acidemia (MMA)
21. Mitochondrial Acetoacetyl-CoA Thiolase Deficiency (3-Ketothiolase Deficiency)
22. Multiple Acyl-CoA Dehydrogenase Deficiency (MADD or Glutaric Acidemia II)

23. Multiple Carboxylase Deficiency
24. Phenylketonuria (PKU)
25. Propionic Acidemia (PA or PPA)
26. Short Chain Acyl-CoA Dehydrogenase Deficiency (SCAD)
27. Short Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency (SCHAD)
28. Sickle Cell Disease
29. Trifunctional Protein Deficiency (TFP Deficiency)
30. Tyrosinemia
31. Very Long Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)

4.2.3.2 Procedures and Follow-Up. Newborn screening is voluntary in Maryland, in that the informed consent of the child's parent/guardian must be obtained before testing. However, the regulations place the responsibility for the implementation of newborn screening on the institution in which the child is born and require the institution to offer screening to any child born in Maryland. There are about 600 out-of-hospital births yearly and the person legally responsible for filing the birth certificate is responsible for offering testing.

Maryland offers screening for babies twice: initially, after 24 hours of milk feedings and then again at about 2 weeks of age. The initial specimen is usually collected at the hospital just before discharge. Specimens drawn before 24 hours of age are not fully satisfactory. Tests run on such specimens are less sensitive in detecting many of the metabolic disorders. Therefore, if the initial specimen is drawn before the baby is 24 hours old, a repeat specimen is requested before the child is 2 weeks old. A subsequent specimen (the third in these cases) is still recommended at the next pediatric visit. The utility of this later screen, given the earlier repeat, is being evaluated.

Normal results on initial specimens are reported by mail from the laboratory to the hospital. Subsequent specimens are usually submitted by the child's pediatrician. Normal results on subsequent specimens are reported by mail from the laboratory to the child's pediatrician. The laboratory includes a copy of the results on any previous specimens submitted on that child. The laboratory also sends a copy of the reports on all subsequent specimens back to the hospital in which the child was born.

Abnormal results are always phoned by the lab to the Office for Genetics and Children with Special Health Care Needs (OGCSHCN), the medical arm of the newborn screening program. OGCSHCN immediately notifies the baby's physician and arranges referral for definitive diagnostic work-up. A physician (board certified in pediatrics and genetics), a nurse, and a genetic counselor handle the calls. The laboratory also sends the child's physician and the hospital copies of the abnormal laboratory report by mail.

Genetic counseling and long-term case management are offered to diagnosed cases. The comprehensive care of patients with inherited metabolic disorders is coordinated with medical geneticists at the following Genetics Centers. Additional consultants/referrals services can be found at *http://www.fha.state.md.us/genetics/html/referrals.html.*

Johns Hopkins Hospital
Center for Medical Genetics
600 N. Wolfe St. Blalock 1008
Baltimore, MD 21287-3914
(410) 955-3071

Children's National Medical Center
Department of Medical Genetics
111 Michigan Ave. N.W.
Washington, DC 20010-2970
(202) 884-2187

University of Maryland
Division of Human Genetics
100 N. Greene St. Room 414
Baltimore, MD 21201-1595
(410) 328-3335

For more information about services available for diagnosed cases, please see *http://www.fha.state.md.us/genetics/html/newprog.html.*

For more information on the Maryland Newborn Screening Program, see *http://www.fha.state.md.us/genetics/html/nbs_ndx.html.*

4.2.3.3 Universal Newborn Hearing Screening. A law was passed during the 1999 Maryland Legislative Session, mandating the establishment of the Universal Infant Hearing Screening Program within DHMH. This law requires that every baby born in a Maryland hospital must be screened for possible hearing loss effective July 1, 2000. OGCSHCN is responsible for administering this program, which identifies and follows-up on newborn babies screened for hearing impairment or at risk for developing hearing impairment.

A baby's hearing is now screened shortly after birth while still in the hospital. Risk factors that might make a baby more likely to have a hearing problem are also collected. The Maryland Infant Hearing Screening & Follow-Up Program helps to ensure that all babies who fail a screening receive follow up testing and early intervention if needed. **For more information, see *http://www.fha.state.md.us/genetics/html/inf_hrg.html***

Selected References

Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children *http://mchb.hrsa.gov/programs/genetics/committee/*

American Academy of Pediatrics–Metabolic/Genetic Screening *http://www.medicalhomeinfo.org/screening/newborn.html*

March of Dimes *http://www.marchofdimes.com*

National Newborn Screening and Genetics Resource Center *http://genes-r-us.uthscsa.edu*