

SECTION 5

Child and Adolescent Health

- Child Development Clinics**
- Pediatric Screening and Genetic Services (PSGS)**
- Virginia Genetics Program**
- Virginia Newborn Hearing Screening**

Child and Adolescent Health

Child Development Clinics

The Child Development Clinics (CDC) are a statewide network of eleven publicly-funded pediatric specialty clinics serving children with known or suspected developmental disorders including mental retardation, communication disorders, learning problems, childhood behavioral, emotional, or mental health disorders, neurological disorders, primary sensory, motor, physical disorders or a combination of these problems.

The mission of the CDCs is to increase the availability and accessibility of comprehensive, interdisciplinary developmental services to appropriate children to promote their optimal physical, social, mental, and emotional development and well-being.

One goal of the clinics is to improve the early identification of children who are at greatest risk for developmental disorders and in need of developmental services. A second goal is to increase the availability and accessibility of comprehensive interdisciplinary developmental services to appropriate children.

The clinics serve Virginia residents from birth through 20 years of age with a suspected or known developmental delay or disorder, behavioral disorder, learning disorder, mental retardation, neuropsychological disorder or presence of severe or multiple risk factors for these conditions.

The clinics diagnose developmental problems including delays in maturation or deviant maturation in physical, social, mental, educational, behavioral, or emotional development to the extent that there is a negative impact on the child's ability to adapt to or cope with the typical environmental demands as expected for chronological age.

The clinics provide a comprehensive evaluation by a team of clinicians. The team usually consists of a pediatrician or nurse practitioner, nurse, clinical social worker, education consultant, and clinical or school child psychologist. This interdisciplinary team provides individual treatment plans for children with developmental disorders. The CDCs are part of VDH's Children with Special Health Care Needs (CSHCN) Program. This program is funded through a combination of federal Title V Maternal and Child Health Block Grant funds and State general funds.

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Pediatric Screening and Genetic Services (PSGS)

Health Issue

There are approximately 95,000 live births in Virginia each year. Of these births, an

estimated 3,700 are born with disorders that may impede their ability to hear, learn, and grow into healthy children and adolescents.

Mission

Pediatric Screening and Genetic Services' (PSGS) focus is to reduce the occurrence and impact of birth defects among children and their families.

Functions

- Assessing pediatric congenital anomalies, including inborn errors of body chemistry and hearing disorders.
- Identifying pediatric screening and genetic resources.
- Informing the public about pediatric screening and genetic services.
- Assisting policy makers in developing pediatric screening and genetic services-related policies.
- Supporting private and public healthcare providers.
- Developing programs and information systems, including the Virginia Infant Screening and Infant Tracking System (VISITS). VISITS is a web-based tracking and data management system that supports the following statewide services:
 - (1) Virginia Early Hearing Detection and Intervention Program
 - (2) Virginia Congenital Anomalies Reporting and Education System
 - (3) Virginia Newborn Screening Services
 - (4) Infant & Toddler Connection of Virginia (via electronic referrals).

Website:

www.welligent.com/visits.

Organization

Pediatric Screening and Genetics Services includes the following programs:

- Virginia Early Hearing Detection and Intervention Program
- Virginia Genetics Program

Contact: Nancy Ford, MPH, RN, Director of Pediatric Screening and Genetic Services, 804-864-7691, Nancy.Ford@vdh.virginia.gov. Website: www.vahealth.org/psgs/

Virginia Genetics Program

The goal of the Virginia Genetics Program is to reduce unnecessary morbidity and mortality from potential or existing genetic conditions by assuring that necessary, high quality, effective genetic health services—including appropriate education, testing, counseling, and treatment—are available to the citizens of the Commonwealth.

Health Issue

- In Virginia, as elsewhere in the United States, birth defects are the leading cause

- of death in the first year of life. Each year in Virginia about 4,600 infants are born with birth defects, of which about 270 infants die before 2 years of age.
- Note: A birth defect is defined as a serious structural, functional, or biochemical abnormality due to genetic, nutritional, or environmental factors, or any combination of the above, that is present at birth even though it may not be manifested until later in life. Such defects range from minor to severe and may result in a physical or mental disability, or early death. The terms “congenital anomaly” and “congenital malformation” are also used to describe such conditions.

Components

- Virginia Newborn Screening Services: Virginia Newborn Screening Services finds those few infants who have the following birth defects. Finding these infants and giving them early treatment prevents serious complications, such as mental retardation, permanent disabilities, or even death. Newborn screening is offered to families with new babies as a service through the Virginia Department of Health. The initial screening tests are performed by the Virginia Department of General Services, Division of Consolidated Laboratories (DCLS), which is located in Richmond. DCLS also performs repeat tests on infants up to 6 months of age. Every infant in Virginia is tested for the following errors of inborn chemistry a few days after birth unless a parent or guardian objects on the grounds that the test conflicts with their religious practice.
 1. Biotinidase Deficiency
 2. Congenital Adrenal Hyperplasia (CAH)
 3. Congenital Hypothyroidism
 4. Galactosemia
 5. Homocystinuria
 6. Maple Syrup Urine Disease (MSUD)
 7. Phenylketonuria (PKU)
 8. Hemoglobinopathies (including Sickle Cell Disease)
 9. Medium-chain acyl-CoA dehydrogenase deficiency (MCAD deficiency)
- Metabolic Treatment Services/Phenylketonuria (PKU) Management:
 1. Metabolic treatment services, including long-term medical management including management of the required metabolic formulas for PKU, MSUD and Homocystinuria, are available for infants and children in medically indigent families from the following health care providers:
 - a. University of Virginia
Division of Medical Genetics
Department of Pediatrics
 - b. Virginia Commonwealth University Medical Center
School of Medicine, Department of Pediatrics
 2. The cost of modified low protein food products required in the management of phenylketonuria are reimbursed to

- a. The parents or guardian of any child.
 - b. Any pregnant woman, who is a legal resident of the Commonwealth and who is diagnosed
 - as requiring treatment for phenylketonuria.
- Virginia Congenital Anomalies Reporting and Education System (VaCARES):
VaCARES is a birth registry of children under 2 years of age who have a congenital anomaly. VaCARES collects epidemiological data and lets families know about treatment programs.
 - Regional Genetic Centers: There are three regional genetic centers that provide genetic testing, counseling, and education for all residents, especially those with very limited resources. (Planning is being done to add a pediatric-serving genetics center in Northern Virginia.)
 1. Virginia Commonwealth University Medical Center
Genetics Program
P.O. Box 980033
Richmond, Virginia 23298
 2. Eastern Virginia Medical School
Department of Pediatrics
Division of Medical Genetics
601 Children's Lane
Norfolk, Virginia 23507-1921
 3. University of Virginia
Division of Medical Genetics
Department of Pediatrics
Box 386
Charlottesville, Virginia 22908
 - Virginia Genetics Advisory Committee: The Committee coordinates access to clinical genetic services across Virginia, assuring the provision of genetic literacy, and quality services and education for consumers and providers taking into consideration issues of confidentiality, privacy, and individual consent. Members include representatives from VDH; Virginia Department of General Services, Division of Consolidated Laboratory Services; Virginia Genetic Centers; Virginia Department of Education; March of Dimes, Virginia Chapter. (Membership is being expanded to include parents and medical associations, and other pertinent organizations.)

Contact: Sharon Williams, M.S., R.N., Virginia Genetics Program Manager, 804-864-7712, SharonK.Williams@vdh.virginia.gov, website <http://www.vahealth.org/genetics/>

Virginia Newborn Hearing Screening

Goal

The goal of the Virginia Early Hearing Detection and Intervention Program is to identify congenital hearing loss in children by 3 months of age and enroll them in appropriate early intervention by 6 months of age.

Health Issue

- Nearly 300 babies are born in Virginia each year with some form of hearing loss—making hearing loss the most frequently occurring birth defect both in the Commonwealth and nationally.
- Experience and research have shown that early detection of hearing loss is essential for promoting the development of infants and toddlers. Conversely, postponed detection of hearing loss often results in developmental delays.

Components

- **Universal Newborn Hearing Screening:** Screening every newborn for hearing loss prior to hospital discharge.
- **Monitoring and Follow-Up:** Ensuring that babies who miss their initial newborn hearing screening prior to hospital discharge receive a screening by the age of 1 month, and/or that children who pass their screenings but have known risk indicators for progressive or late-onset hearing loss receive ongoing assessment through 6 years of age.
- **Diagnostic Audiology:** For those infants who refer following their newborn hearing screening, conducting a diagnostic audiological evaluation before 3 months of age to confirm and quantify/qualify (i.e., determine the type, degree and configuration of) the hearing loss and to assist families in identifying appropriate amplification and/or communication methods.
- **Care Coordination:** Promoting the concept of the medical home to ensure that other evaluations (e.g., vision and genetics screenings) are conducted, as appropriate, and to coordinate the overall health care needs of children who have hearing loss.
- **Early Intervention:** Enrolling infants with hearing loss in early intervention services by 6 months of age.

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