What is VCFS?

Texas Department of Assistive and Rehabilitative Services (DARS)

Division for Early Childhood Intervention Services (ECI)

ECI programs serve families with children birth to 36 months with developmental delays or disabilities. ECI provides family support and specialized services to strengthen the family’s ability to access resources and improve their child’s development through daily activities. Services are available in every county in Texas.

The state agency responsible for ECI is the Department of Assistive and Rehabilitative Services. DARS contracts with local agencies to provide services in every Texas county.

To learn more about ECI call the DARS Inquiries Line: 1-800-628-5115 or if you have a hearing impairment call the TDD/TTY line at 1-866-581-9328 or visit the ECI web pages on the DARS website at www.dars.state.tx.us/ecis
In the interest of early identification and because your child was found to have two or more of the characteristics listed on the Velo-Cardio-Facial Syndrome (VCFS) checklist, the State of Texas requires that you receive additional information about VCFS. Please note, however, that the presence of these characteristics does not necessarily mean your child has VCFS.

What are some of the characteristics and symptoms of VCFS?
Children with VCFS often have minor learning, speech and/or feeding problems. However the characteristics and symptoms of VCFS can vary widely between children which makes it difficult to diagnose. Listed below are some of the characteristics that children with VCFS may exhibit.

- Long face with prominent upper jaw
- Flattening of the cheeks
- Underdeveloped lower jaw
- Bluish color below the eyes
- Prominent nose with narrow nasal passages
- Thin upper lip with a down-slanted mouth
- Multiple abnormalities of the heart
- Learning disabilities in one or more areas
- Hearing loss
- Speech problems
- Extreme behaviors/mood swings

NOTE: It is important to understand that a child with VCFS usually does not have all of these characteristics.

Over 180 symptoms may occur in VCFS. They can include nearly every organ system in the body with broad-reaching effects on development and behavior, including speech, language, personality, mood, learning, attention, and temperament.

Many of the body systems that influence a child’s development can be involved, such as:
- Immune system (helps to fight off infections)
- Endocrine system (the glands that secrete hormones for normal growth and development)
- Neurological system (brain control centers for speech and hearing, learning, and moods)

How is VCFS diagnosed?
Because VCFS can affect children in many different ways, and because it’s associated with so many varying symptoms — many of which are associated with other disorders, too — it can be difficult to diagnose. In fact, many parents consult a number of doctors before their child’s problem is finally pinpointed.

If your child’s doctor suspects your child has VCFS, the doctor should make a referral for testing to confirm the diagnosis. A highly accurate blood test called FISH (fluorescence in situ hybridization) can confirm the diagnosis.

What are Common Treatment Options?
Because a person’s genetic makeup can’t be changed, doctors can’t “cure” VCFS. But once there is a diagnosis, the doctor will usually recommend that the child undergo evaluation in the areas that VCFS affects. Once medical or developmental problems are identified, doctors can develop plans that will help manage them. In addition to a geneticist, a child with VCFS may need to be treated by a cardiologist, immunologist, audiologist, speech-language pathologist, otolaryngologist, endocrinologist, surgeons, or psychologist.

What resources are available for families who have a child with VCFS?
There are many resources available for families who have a child with VCFS.

VCFS Texas, Inc.
1717 Briar Street, Austin, Texas 78704
VCFS Texas, Inc. provides “support and resources to individuals with VCFS, their families, professionals, and the community in Texas.”
E-mail: info@vcfstexas.com
www.vcfstexas.com

VCFS Educational Foundation
P.O. Box 874, Milltown, NJ 08850
1-866-VCFSEF5 (1-866-823-7335)
The foundation’s purpose is to educate the public, the scientific community, families of individuals with VCFS, and individuals with VCFS about this common genetic disorder.
www.vcfs.org

ECI Resource Guide
The ECI Resource Guide contains a wealth of information about services for children with developmental delays or disabilities. The ECI Resource Guide has information about Medicaid and Non-Medicaid Waiver Programs (see page 4).

The Department of Aging and Disability Services (DADS) maintains the Medicaid and Non-Medicaid Waiver Programs. To find out about these programs, visit: www.dads.state.tx.us/services/faqs-fact

If you did not receive an ECI Resource Guide and would like to place an order, contact the DARS Inquiries Line at 1-800-628-5115 or if you have a hearing impairment, call the TDD/TTY line at 1-866-581-9328.