

What Is Velo-Cardio-Facial Syndrome (VCFS)?

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 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 the diagnosis 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.

Nonprofit Organizations

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: contact@22qTexas.org

www.vcfstexas.com

International Chromosome 22q11 Foundation

www.22q.org

22q is a non-profit organization that was founded by parents in an effort to bring awareness and support for this rare and under-recognized condition.

Support Groups

Support groups are established to help parents and family members learn about caring for a person with VCFS. The groups are educational and supportive in nature, and may be able to refer you to resources in your community.

Note: Support groups are not medical service providers, nor do they give medical advice or opinions. Medical advice should be obtained only from a qualified medical professional.

The following are contacts for local support groups in Texas:

Austin Area

Courtney Helford

512-332-0368 or 512-304-5669

Email: courtneyhelford@yahoo.com

Debra Trejo (se habla Español)

512-909-8359

Email: DTrejo@kempsmith.com

Dallas Area

Heather Holder

Email: heather22q@gmail.com

Houston Area

Megan Wawarofsky

832-630-9918

Email: mwawarofsky@yahoo.com

Health and Human Services Commission (HHSC) 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 Health and Human Services Commission. HHSC contracts with local agencies to provide services in every Texas county.

To learn more about ECI call the HHS Office of the Ombudsman: 1-877-787-8999. If you are a person who is deaf or hard of hearing, use the relay option of your choice. For more information, visit the ECI web pages on the HHS website at hhs.texas.gov/eci

ECI Resource Guide

The [ECI Resource Guide](#)¹ contains a wealth of information about services for children with developmental delays or disabilities.

¹ URL: <https://hhs.texas.gov/services/disability/early-childhood-intervention-services/eci-central-directory-resources/eci-resource-guide>