VELOCARDIOFACIAL SYNDROME (VCFS) & 22Q11.2 DELETION SYNDROME

What it is: VCFS or 22q11.2 deletion syndrome is a genetic condition that occurs before a child is born. It is caused by a missing piece of genetic material on chromosome 22. The 22q11.2 deletion is one of the most common genetic disorders and is almost as common as Down Syndrome. VCFS is present in 1 of every 4,000 live births; in 1 in 68 children with congenital heart disease; and in 5 to 8 percent of children born with cleft palate. VCFS can cause a wide range of health problems. No two people are ever exactly alike, and this syndrome may not affect any two people the same way.

Other names for the 22q11.2 syndrome: DiGeorge syndrome (DGS), velo-cardio-facial syndrome (VCFS), conotruncal anomaly face syndrome (CTAF), Opitz G/BBB syndrome, and Cayler cardiofacial syndrome. There are no detectable differences in the deletions of genetic material found in people with VCFS versus those with other related syndromes. Individuals with these diagnoses all have the same underlying condition of 22q11.2 deletion syndrome.

There are many possible conditions associated with VCFS including combinations of conditions:

- heart defects
- feeding and gastrointestinal difficulties and growth delays
- immune system deficits
- cleft palate
- kidney problems
- hearing loss
- low calcium and other endocrine issues
- delays in language and speech development
- behavioral and emotional difficulties (ADHD, autism, anxiety, etc.)

Having one or more of the above conditions does not necessarily mean a diagnosis of VCFS.

What to do: Anyone who suspects that a child may have VCFS should have the family contact their child's physician to discuss their concerns. The doctor may recommend certain tests or referrals to diagnose the problems and medical procedures to treat the conditions. In addition, children with one or more of the listed conditions may not have VCFS. EarlySteps will support the family in meeting the child's developmental needs and in accessing resources.

Where to go:

State Resources

Children Special Health Services (CSHS)

The CSHS program is the principle Office of Public Health agency ensuring that children and youth who have special health care needs in Louisiana have access to health care services designed to minimize their disabilities and maximize their probabilities of enjoying independent and self-sufficient lives. Locations, contact information and other helpful resources for CSHS can be found at: http://new.dhh.louisiana.gov/index.cfm/page/1550

EarlySteps Community Outreach Specialists and Families Helping Families

EarlySteps Community Outreach Specialists (COSs) are family members of children with disabilities working with Families Helping Families organizations and Southeast Louisiana AHEC. COSs are available to assist families in EarlySteps for parent to parent support, provide information and link families with community resources. The list of COSs is available on the parent page of the EarlySteps website at: http://new.dhh.louisiana.gov/index.cfm/page/215. Of course, EarlySteps is available to assist the family with their concerns. Families can ask their child's family support coordinator for assistance.

Louisiana 22q Support Network

Phone: 504-250-1916 Email: 22q11la@gmail.com
Find the network on Facebook at http://www.facebook.com

National Resources

The International 22q11.2 Foundation: http://www.22q.org

VCFS Educational Foundation: http://www.vcfsef.org

Dempster Family Foundation: http://www.dempsterfamilyfoundation.org

After EarlySteps:

Families should contact their local human services district or authority (HSD/As) for assistance through the office that administers developmental disability services, including the Medicaid Waiver program, State-funded supports, and referrals for Medicaid EPSDT case management.

The list of regional HSD/As can be found at:
http://new.dhh.louisiana.gov/index.cfm/page/134/n/137

{VCFS information in this document was taken from the national resources listed above.}