

# FACES:

The National Craniofacial Association 1-800-332-2373

## What is Velo-cardio-facial Syndrome?

Velocardiofacial Syndrome, also known as VCFS or as 22q11.2 Syndrome or DiGeorge Syndrome is the most common syndrome associated with cleft palate. Approximately 1 in 2,000-5,000 children are born with VCFS. Characteristics include:

- a long face with a prominent upper jaw
- flattening of the cheeks
- an underdeveloped lower jaw
- a bluish color below the eyes
- a prominent nose with narrow nasal passages
- a long thin upper lip and a down-slanting mouth
- cleft palate or submucous cleft palate

## Why did this happen?

Velocardiofacial Syndrome is an autosomal dominant condition. Genetic studies of children with this condition show that a microscopic segment on the long arm of chromosome 22 is missing. The genetic test for diagnosis of this condition is called "FISH analysis" and can be performed in many medical centers. It is not because of anything the mother did or did not do during the pregnancy.

## Will this happen to children I have in the future?

If neither parent has VCFS, the chances are small that other children will be born with VCFS. If one parent is affected, there is a 50% chance that he or she will pass VCFS to a child. Genetic testing can be done to identify the presence of VCFS.

## What kinds of problems could my child have?

In addition to the physical characteristics common to VCFS, your child could have some of the following problems:

- multiple abnormalities of the heart
- learning disabilities in one or more areas
- hearing loss
- problems with speech
- leg pain
- extremes of behavior

## Will my child need surgery?

Depending on the severity of Velocardiofacial Syndrome, your child may have some or all of the following surgeries:

- repair of the cleft palate
- repair of the lower jaw
- reconstructive surgery on the ear
- surgery to repair other facial features

**New advances in procedures to treat Velocardiofacial Syndrome are constantly being developed. Be an advocate for your child!**

## **How do I get help for my child?**

Your child should be treated by a qualified craniofacial medical team at a craniofacial center. Currently, FACES has information on many of these teams. This is by no means a comprehensive list of all the craniofacial teams. Please contact FACES for details.

## **Am I alone?**

No! There are many families and organizations who will be glad to talk with you and help you with information and support. Don't forget books, videos, and websites. The listing below will get you started.

FACES: The National Craniofacial Association  
P.O. Box 11082  
Chattanooga, TN 37401  
(800) 332-2373

email: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)

website: [www.faces-cranio.org](http://www.faces-cranio.org)

*We provide financial support for non-medical expenses to patients traveling to a craniofacial center for treatment. Eligibility is based on financial and medical need. Resources include newsletters, information about craniofacial conditions, and networking opportunities.*

Virtual Center for VCFS  
138 Solomon Seal Lane  
Manlius, NY 13104  
(315)559-4685

email: [info@vcfscenter.com](mailto:info@vcfscenter.com)

website: [www.vcfscenter.com](http://www.vcfscenter.com)

*Excellent resource!! This very informative group was started by Dr. Robert Shprintzen and has grown quickly.*

National Health Law Program  
1444 I Street, NW - Suite 1105  
Washington, DC 20005  
(202) 289-7661

website: [www.healthlaw.org](http://www.healthlaw.org)

*Provides extensive information on health care laws affecting families of children with special needs.*

*Missing Genetic Pieces: Strategies for Living with VCFS, The Chromosome 22q11.2 Deletion*  
Written by Sherry Baker-Gomez.

website: [www.everythingfamily.net](http://www.everythingfamily.net)

*A wonderful website and book, includes developmental, educational, financial and support issues. A comprehensive handbook for families with any genetic disorder or disability.*

Book also available at: [www.amazon.com](http://www.amazon.com)

*Children with Facial Difference: A Parent's Guide.*  
Written by Hope Charkins, MSW

*Excellent resource for parents to help them cope with medical, emotional, social, educational, legal, and financial challenges presented by facial differences of their children. Look for this book at your larger bookstore chains.*

Available at: [www.Amazon.com](http://www.Amazon.com)

Yahoo Family Support Group:

<http://groups.yahoo.com/group/vcfsfamilysupport/>