

**The Tenth Annual International Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation, Inc. and
The Fourth International 22q11.2 Deletion Conference
Joint meeting**

**July 23-25, 2004
Atlanta, Georgia USA**

About Velocardiofacial Syndrome (VCFS)

VCFS is one of the most common genetic syndromes in humans that, as its name suggests, is typically characterized by cleft palate, velopharyngeal insufficiency, or both, cardiac anomalies, a characteristic facial appearance, and a large number of other abnormalities. It is caused by deletion of a small region of genetic material from Chromosome 22. Therefore, VCFS is sometimes referred to by its "genetic" designation, 22q11.2 deletion. The disorder caused by this deletion is also referred to by other names, including DiGeorge Syndrome, Conotruncal Anomalies Face Syndrome (CAFS), Sedlackova Syndrome, CATCH 22, and Shprintzen Syndrome. This deletion affects fetal development of the brain, heart, thymus, pharynx, parathyroid glands, and other organs, and, as a result, causes many different health, developmental, and behavioral problems. The 22q11.2 deletion is the most common genetic cause of congenital heart defects and learning disorders after Down syndrome.

It is estimated that one child in every 1,800 is born with the 22q11.2 deletion. These children can face a lifetime of care and treatment for over 180 different medical, developmental and behavioral conditions. Because diagnosis can be difficult, the disorder may not be diagnosed for years.

About the Organizations

The **Velo-Cardio-Facial Syndrome Educational Foundation, Inc. (VCFSEF)** was founded in 1994 as an organization of professionals and lay people whose purpose is to spread information about velo-cardio-facial syndrome (VCFS), one of the most common genetic syndromes in humans. The mission statement of The Foundation is as follows:

The Velo-Cardio-Facial Syndrome Educational Foundation (The Foundation) is an organization comprised of both professional and lay people whose purpose is to educate the public, the scientific community, families of individuals with velo-cardio-facial syndrome, and individuals with velo-cardio-facial syndrome (VCFS) about this common genetic disorder. The Foundation will act as an advocate for both patients with VCFS and the professional community treating this disorder. The Foundation will provide a forum for the advancement of knowledge relevant to the diagnosis and treatment of individuals with VCFS. The Foundation will provide a forum for discussion of the problems, treatments, or achievements associated with VCFS and its management.

The Foundation has held nine annual meetings in the U.S. and Europe reaching nearly 3000 people and its newsletter and web site (www.vcfsef.org) have been reached by tens of thousands of people from around the world. Plans for future meetings in Europe and Australia are underway. The Foundation membership is several thousand strong and includes people from all over the world including some of the most eminent scientists studying this common disorder. Incorporated as a 510(c)3 Foundation in 1999, The Foundation is a fully independent non-profit organization, not affiliated with any institution, and is run by and for its membership and the hundreds of thousands of people worldwide who have VCFS. Anyone interested in VCFS is invited to join The Foundation by going to the Membership page on the website.

The **Fourth International 22q11.2 Deletion Conference** is a semiannual conference initiated to provide another international forum for dialogue on 22q11.2 deletion. The first 22q11.2 Deletion International Conference was held in 1998 in Strasbourg, France with subsequent conferences in Philadelphia, Pennsylvania (2000) and Rome, Italy (2002). These meetings provided a forum for professionals around the globe to present their clinical and basic science research. The meeting in Philadelphia also included parents. The conference in Atlanta will continue this effort by holding the meeting jointly with the Velocardiofacial Syndrome Educational Foundation, Inc.

The Fourth International 22q11.2 Deletion Conference is not affiliated with any institution and is hosted by Institutions in the host city. We all join with The Velo-Cardio-Facial Syndrome Education Foundation, Inc in inviting clinicians, researchers, parents and families to participate in what is planned to be a stimulating exchange of ideas, challenges, questions, and solutions.

This exciting meeting is being sponsored jointly by The Velo-Cardio-Facial Syndrome Educational Foundation, Inc., the Fourth International 22q11.2 Deletion Conference, and Children's Healthcare of Atlanta.

About the Meeting

The meeting to be held in Atlanta in July 2004 will be the Tenth Annual International Conference of the Velocardiofacial Syndrome Educational Foundation, Inc. and the Fourth International 22q11.2 Deletion Conference. It will be the first time these two conferences convene simultaneously. The purpose of the three-day conference is to join VCFS researchers, practitioners, and families from around the world to educate one another on the latest discoveries and innovative treatments, to share experiences, and to provide management and support strategies.

A unique feature of VCFSEF conferences is that, in addition to professional and lay presentations and discussions, individuals with VCFS have the opportunity to attend brief clinics held by renowned experts in speech-language pathology, feeding, and foot pain. These clinics will be offered again at the Atlanta meeting. We will also arrange informal topic-oriented discussions of interest to professionals and parents of children with VCFS.

Learning Objectives

By the conclusion of the conference, participants will:

1. Describe the 22q11.2 deletion phenotype and diagnostic process to increase the accuracy of evaluation and treatment of affected individuals.
2. Recognize the scope of medical and surgical problems associated with the deletion and describe effective triage and treatment.
3. Describe the brain structure and function of patients with VCFS.
4. Describe educational issues and appropriate classroom modifications that are effective for children with VCFS.
5. Describe speech and language issues associated with VCFS and appropriate treatment.
6. Describe the behavioral and psychological issues associated with VCFS and their implications
7. Recognize the indications for and availability of prenatal diagnosis.

Program Committee

Karlene Coleman, MN, Co-Chairperson
Karen J. Golding-Kushner, Ph.D., Co-Chairperson
Maureen Anderson
David Ledbetter, M.D.
William Mahle, M.D.
Robert Shprintzen, Ph.D.

Program Coordinator

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Target Audience

The target audience for this conference is physicians, researchers, genetic counselors, speech-language pathologists, audiologists, regular and special education teachers, health educators, nurses, social workers and other health professionals involved in providing care for people with the 22q11.2 deletion, and families interested in or with 22q11.2 deletion.

All programs are intended to be accessible to all persons. If you have a disability and require assistance in order to fully participate in the conference activities, please call the conference coordinator to discuss your specific needs.

Conference Location and Travel

The conference will be held at the Sheraton Colony Square Hotel - Mid-Town Atlanta at 188 14th Street NE, Atlanta, GA 30361. The Sheraton Colony Square Hotel is within walking distance of the best shopping, restaurants, and entertainment in the southeast. The hotel guestroom rate for this program is \$95 for single or double plus sales and local taxes, currently 14%. To register, call the reservation line for the hotel at 1-866-912-1171. *Please indicate that you are attending the conference sponsored by Children's Healthcare of Atlanta.* The reservation deadline is June 22, 2004. After that date, reservations will be on a space available basis, and the group rate cannot be guaranteed.

Hartsfield-Jackson Atlanta International Airport is the airport nearest the conference venue. The hotel is 15 minutes from Hartsfield-Jackson Atlanta International airport. Guests can travel conveniently by Metropolitan Atlanta Rapid Transit from the airport to the Arts Center Station, just a short walk (approximately 3 blocks) from the Sheraton Colony Square Hotel. There are also airport shuttles and taxis available at the airport.

Supporters

Centers For Disease Control
Children's Healthcare of Atlanta Foundation
Department of Genetics, Emory University School of Medicine
Georgia Health Foundation, Inc.

For more information about the Velo-Cardio-Facial Syndrome Educational Foundation, Incorporated go to <http://www.vcfsef.org>

Conference coordination by Children's Healthcare of Atlanta (<http://www.choa.org/professionals/cme.shtml>).

CALL FOR ABSTRACTS

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COVER PAGE:

1. Title of Presentation: (ALL CAPS PLEASE) _____

2. Submitted by (underline person presenting and include Institution, City, Country):

3. Full mailing address including Institution & Country of Presenter

4. Phone number: _____

5. Fax number: _____

6. E-mail address of corresponding presenter:

7. Type of presentation preferred: (Please check desired category. The Planning Committee reserves the right to choose the format for the presentation.)

_____ Professional paper (15 minutes)

Note: A limited number of 30-minute seminars may be available.

Please check here if you prefer a 30-minute seminar _____

Explain why you need additional time: _____

_____ Multi-center Symposium (45 min)

(Intended to encourage inter-institutional cooperation and collaboration)

_____ Brief Clinical Report (5 min)

_____ Lay presentation: Sharing the good times (5 min)

_____ Lay presentation: Practical solutions (5 min)

_____ Poster session

8. Check category

_____ Basic science

_____ Clinical research

_____ Case studies

_____ Other (Specify): _____

9. Indicate discipline: (Please circle)

Cardiology

Endocrinology

Immunology

Speech/Lang

Psychiatry/Behavior

Renal

Surgery

Support

Nursing

Education

Parenting

Other (specify) _____

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Page 2:

1. Title of Presentation: (ALL CAPS PLEASE)

2. Submitted by (underline person presenting and include Institution, City, Country):

Abstract: (Abstracts must be typed in English and contain a maximum of 250 words)

Directions for submission:

All submissions should include two pages:

Page 1: Cover page with all information completed

Page 2: Abstract with title and authors at top of page

Submit in Microsoft Word format

Electronic submission preferred. E-mail abstract with all required information to:
gail.klein@choa.org

If submitting by mail, send original WITH document in Word format on computer disc or CD to:

Gail Klein, BSN, RN

Continuing Education

Children's Healthcare of Atlanta

1600 Tullie Circle, NE

Atlanta, Georgia 30329

Deadline for submission:

Papers will be reviewed and authors notified as they are received. Final deadline for submission of abstracts is **March 15, 2004**. Papers submitted later will be considered at the discretion of the planning committee.

For more information contact:

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