

10th Annual International Meeting of The Velo-Cardio-Facial Syndrome Education Foundation



Atlanta Georgia
July 23 - 25, 2004

General Agenda for the 3 Days

❖ Plenary Session

- Epidemiology
- **Prevalence** of VCFS in Western Sweden
- World recognition of VCFS

❖ Molecular Genetics

❖ Communication Impairment

- **Speech and language Issues**
- Why VPI with or without Clefts
- Treatment of speech and Language Disorders in VCFS

General Agenda for the 3 Days (continued)

❖ Clinical and Personal Perspectives

- Consistent Evaluation And Intervention
- From a Parent's Perspective: Coordinating Your Child's Care
- Three Generations with DiGeorge
- The Role of Charities and Support Groups

❖ Clinical Genetics

- What is and is not deletion
- Familial Recurrences
- Much ado about 22q11
- Diagnosis, Natural History

General Agenda for the 3 Days (continued)

❖ **Surgery and Speech**

- Submucous Cleft Palate
- Longitudinal Study of Speech and Language
- Communication issues in the Australian population
- Speech production and phonological processing

❖ **Psychiatry, Behavior and Neuroscience**

- Basic timing mechanism in VCFS
- A cross-syndromal comparison of cognitive profiles
- Behavior problems in relation to intelligence in children
- Neuropsychiatric aspect and coping in familial cases

General Agenda for the 3 Days (continued)

❖ Feeding Disorders

❖ Neural Imaging and Behavior

- Brain structure
- Brain imaging, development, cognition, memory
- Brain Imaging and other markers
- Cognitive and behavioral parameters associated with VCFS
- Personalities profiles in youth

General Agenda for the 3 Days (continued)

❖ Psychiatry

- Risk Factors for ADHD in VCFS
- What can VCFS tell us about the genetics of Schizophrenia
- **Autism spectrum** disorders associated with 22q11 deletions
- **Psychiatric disturbance in adults with VCFS**

General Agenda for the 3 Days (continued)

❖ Education and Living Skills

- General Memory Function in children and young adults
- Nonverbal learning
- Voyage into adulthood
- Impact of VCFS on learning and school performance and what can be done
- **Cognitive and behavioral parameters associated with VCFS**

❖ Cardiology

❖ Immunology, Medical Emergencies and Dentistry

Concurrent Sessions

- ❖ Speech and Language Issues
- ❖ What's in a Name
- ❖ Issues in Education
- ❖ Leg Pain and Their Management
- ❖ Sibling Relationships
- ❖ Tips for Parents of Teens
- ❖ Support Groups
- ❖ Coping with Behavioral and Psychological Issues
- ❖ Estate Planning
- ❖ Clinical and Molecular Genetics
- ❖ Ask the Cardiologist
- ❖ Teen Talk

A Little More Detail

❖ Prevalence

- 2003 data
- 1.7 per 10,000 births

❖ Speech and language Issues

- 96% of people with VCFS are language delayed
- Pharyngoplasty vs. pharyngeal flap

❖ From a Parent's Perspective: Coordinating Your Child's Care

- Be proactive - "you are the professional parent"

❖ Psychiatry, Behavior and Neuroscience

- Schizophrenia is prevalent in this population (23% of VCFS population vs. 1.3% of general population)
Canadian study
- social and attention problems are prevalent
 - withdrawal
 - complaints stomach aches, headaches
- seek mental health advice early

A Little More Detail (continued)

❖ Cognitive and behavioral

- 30% of VCFS population are ADHD
- children tend to become more withdrawn and internalized with age

❖ Autism spectrum

- 14% in VCFS population vs. .2% in general population
- lower than first expected however

❖ Psychiatric disturbance in adults with VCFS

- develop in late teens or older
- Bipolarism not showing up at higher rates
- Ionized calcium levels are a clue
- Manage your child's stress levels to delay or reduce the onset of psychiatric issues

Our Personal Highlights / Notes

- ❖ Opportunity to interact with highly knowledgeable professionals one on one
 - Knowledgeable parents
 - Medical doctors with specific areas of expertise
 - Psychiatric specialists
- ❖ Personal accounts of fairly high degrees of independence
- ❖ Advocate, advocate, advocate (educational systems)
- ❖ Tips and tricks
 - Cell phones
 - On Star® style services
- ❖ Missing Genetic Pieces, Strategies for Living With VCFS by Sherry Baker-Gomez

All in all a very educational and helpful experience. We highly recommend to any of you who can, to attend....

11th Annual International Meeting of The
Velo-Cardio-Facial Syndrome Education
Foundation
to be held in



Syracuse New York