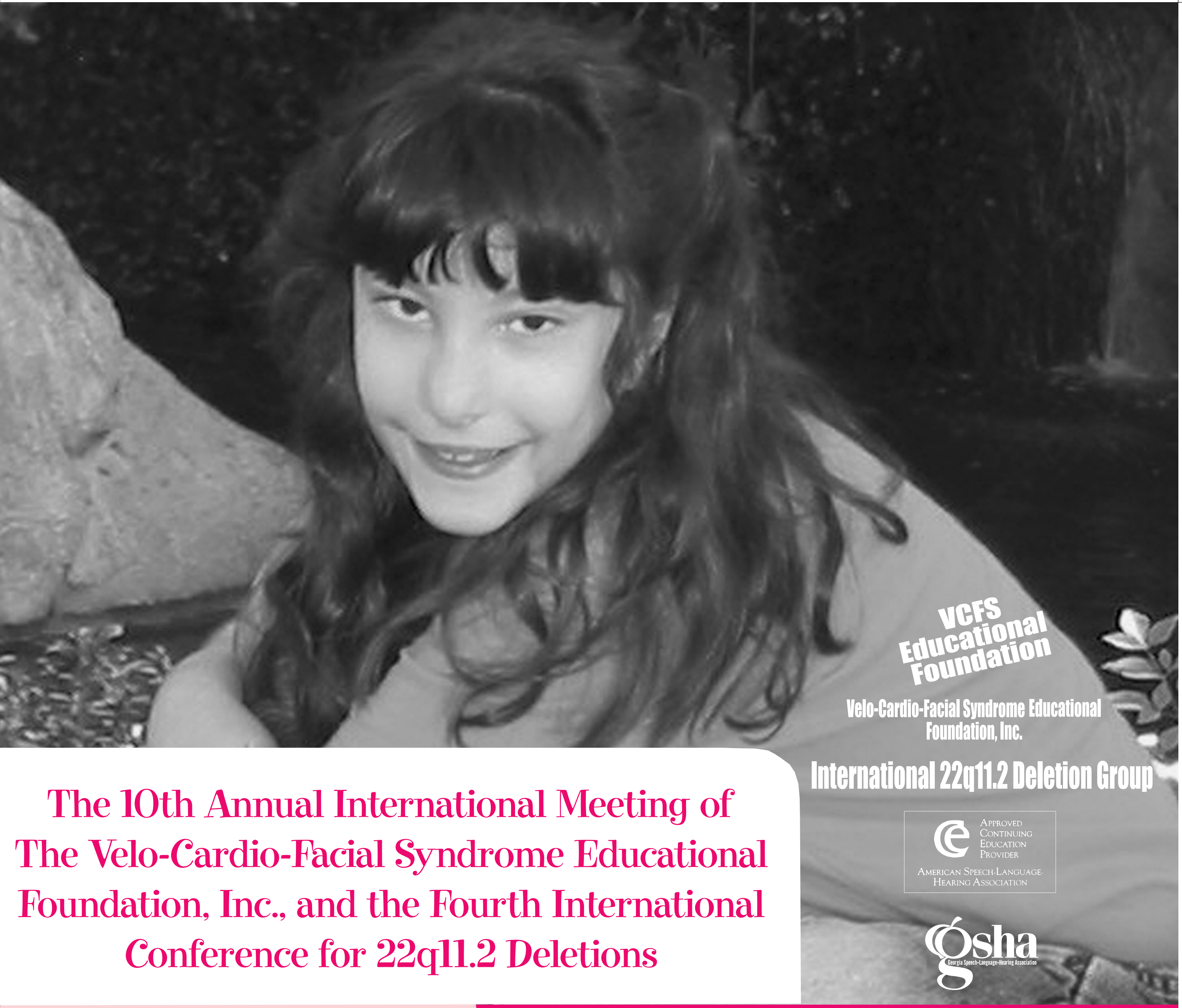

VCFS Educational Foundation

Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

International 22q11.2 Deletion Group

Approved Continuing Education Provider
American Speech-Language-Hearing Association

gsha
Georgia Speech-Language-Hearing Association

The 10th Annual International Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc., and the Fourth International Conference for 22q11.2 Deletions

July 23-25, 2004

Sheraton Midtown Atlanta Hotel
at Colony Square

Children's Healthcare of Atlanta

Atlanta, Georgia

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http://www.choa.org/
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REGISTRATION

The 10th Annual International Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.,
and The Fourth International Conference for 22q11.2 Deletions
Sheraton Midtown Atlanta Hotel at Colony Square, Atlanta, Georgia • July 23-25, 2004

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Please notify me of upcoming conferences sponsored by:
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☐ Velo-Cardio-Facial Syndrome Educational Foundation, Inc.
☐ International 22q Group

☐ I would like to learn more about opportunities at Children's Healthcare of Atlanta

Registration Fee: (includes three continental breakfasts, Saturday lunch, and course materials)

☐	$150	Individual	
☐	$ 50	Spouse/partner/guest	
☐	$ 20	Each child age 5 and over	#_______
☐	$ 0	Children under age 5	#_______
		$275 Family registration maximum (excluding late fee, additional CEU fee, and Saturday evening dinner)	
☐	$ 25	**Late Registration fee** *(for registrations received after June 22, 2004)*	
☐	Additional $ 20	CEU fee for genetic counselors *(if CEUs desired)*	

Optional All-Attendee Dinner Saturday evening July 24 (reservation and payment **required**):
Note: *This is in addition to the family registration maximum.*

☐	$ 30	Each Adult	#_______
☐	$ 15	Each child age 5 and over	#_______
☐	$ 0	Children under age 5	#_______

$ _______ enclosed

Type of Payment

Credit Card *(circle one)* Visa MC AMEX Discover

Card Number Expiration Date Amount to be Charged

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Check *(please make payable to Children's Healthcare of Atlanta)*

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Please complete and return form with payment to: Children's Healthcare of Atlanta, Continuing Education, 1600 Tullie Circle NE, Atlanta, GA 30329-2303; Phone: 404-785-7840; Fax: 404-785-7673. Space is limited. Please mail in your registration promptly to secure your participation. The course will be filled on a first-come, first-served basis. Telephone registrations will not be accepted.

Refund Policy: *If you must cancel your registration, notify us at least seven days before the course and we will issue a refund (minus a $25 administrative fee). No-shows or cancellations received less than seven days prior to the course are ineligible for a refund.*

Friday July 23, 2004

7:30 a.m. **Registration and Continental Breakfast**
**Optional "Birds of a Feather" seating opportunity*

9 a.m. **Welcome**
Jay Berkelhamer, M.D.
Senior Vice President of Medical Affairs
Children's Healthcare of Atlanta
Atlanta, Georgia

9:05 a.m. **Opening Remarks**
Karen J. Golding-Kushner, Ph.D.
Velo-Cardio-Facial Syndrome Educational Foundation, Inc.
and
William T. Mahle, M.D.
International 22q11.2 Deletion Group

9:15 a.m. **Session One: Plenary Session**
Moderator: *David H. Ledbetter, Ph.D.*
Keynote Address: *Raju Kucherlapati, Ph.D.*
Epidemiology: The Prevalence of VCFS
Adolfo Correa, M.D., Ph.D.
Prevalence of VCFS in Western Sweden
Solveig Oskarsdottir, M.D.
A Review of World Recognition of VCFS
Stephan Eliez, M.D., P.D. Stephen Russell,
Antonio Ysunza, M.D., Sc.D., Julie Squair,
Ahmad Al-Khattat, Ph.D., Doron Gothelf, M.D.

11:05 a.m. Break

11:15 a.m. **Session Two: Molecular Genetics**
Moderator: *David H. Ledbetter, Ph.D.*
Mouse Models and What They Tell Us About VCFS
Bernice Morrow, Ph.D.
Candidate Genes in VCFS, *Beverly Emanuel, Ph.D.*
COMT: Can its Role Lead to Effective Treatments?
William Graf, M.D.

12:40 p.m. Lunch on your own
**Optional "Birds of a Feather" seating opportunity*

1:50 p.m. **Session Three: Communication Impairment**
Moderator: *Susan Marks, M.S., C.C.C.*
Speech and Language Issues in 22q11.2 Deletion
Cynthia B. Solot
Why Do Children with VCFS have VPI With or Without Clefts?, *Robert J. Shprintzen, Ph.D.*
Assessment of Speech and Language Disorders in VCFS-Special Considerations, *John E. Riski, Ph.D.*
Treatment of Speech and Language Disorders in VCFS-Special Considerations, *Karen J. Golding-Kushner, Ph.D.*

3:15 p.m. Break

3:25 p.m. **Session Four: Surgery for Speech**
Moderator: *Eileen Marrinan, M.S., M.P.H.*
Evaluation of Pharyngoplasty, *Fernando Burstein, M.D.*
Treatment of VPI, *Albert Losken, M.D.*
Pharyngeal Flap: Maximizing Outcomes
Minimizing Complications, *Sherard A. Tatum, M.D.*
Abstract Presentations and Panel Discussion with Audience Interaction-Outcomes of Speech Treatment in VCFS,
Fernando Burstein, M.D., Karen J. Golding-Kushner, Ph.D.,
John E. Riski, Ph.D., Cynthia B. Solot, Sherard A. Tatum, M.D.

Session Four A: Abstract Presentations Psychiatry
Moderator: Anne S. Bassett, M.D.

5:30 p.m. Adjourn

5:45 p.m. **Annual General Membership Meeting,**
VCFS Educational Foundation, Inc.

**"Birds of a Feather" seating opportunities at breakfast and lunch are optional. Participants who choose this option will be seated together based upon interest group (geneticists, adults with 22q11.2 deletion, parents of teens, SLPs). If interested, sign up for "Birds of a Feather" at registration on July 23.*

Saturday July 24, 2004

7 a.m. **Continental breakfast with optional interactive breakout sessions**

(Register for sessions at check-in. Registration limited). These sessions offer an opportunity to ask questions and engage in topic-oriented discussions in a small group.

A. Speech and Language Issues
Karen J. Golding-Kushner, Ph.D.
– Q&A and discussion for professionals and parents

B. What's in a Name? 22q11.2 Deletion Syndrome
Angelo DiGeorge, M.D., Robert J. Shprintzen, Ph.D., and Nathaniel Robin, M.D.
– Presentation, Q&A, and discussion for professionals and parents

C. Issues in Education, Donna Cutler-Landsman, B.S., M.S.
– Designed for professionals and parents

D. Leg Pains and Their Management, Ahmad Al-Khattat, Ph.D.
– Designed for professionals and parents

8 a.m. **Session Five: Clinical Genetics**
Moderator: *Nicole Philip, M.D.*
Variability of Phenotype: Implications for Phenotype to Genotype Matching, *Nathaniel Robin, M.D.*
Familial Recurrences of VCFS, *M. Cristina DiGilio, M.D.*
Much Ado About 22Q, *Donna M. McDonald-McGinn, M.S., C.G.C.*
Initial Presentation, Ascertainment and Diagnosis in Children with 22q11.2 Deletion Syndrome: A 10-year Experience in a Tertiary Pediatric Hospital in Japan
Hiroshi Kawame, M.D.

10:10 a.m. Break

10:20 a.m. **Session Six: Feeding Disorders**
Moderator: *Dominique Pfeiffer*
Feeding Disorders: Assessment and Treatment
Robert Beecher, M.S., C.C.C-S.L.P.
The Myth and Facts About "Swallowing Disorders" in Children with VCFS, *Robert J. Shprintzen, Ph.D.*
Abstracts and Questions

12:15 p.m. **Lunch provided with optional interactive breakout sessions**

(Register for sessions at check-in. Registration limited) These sessions offer an opportunity to ask questions and engage in topic-oriented discussions in a small group.

E. Estate Planning, *Keith Hallman, C.F.P., C.L.U., Ch.F.C., R.H.U., R.E.B.C.*
– Presentation and Q&A for Parents

F. Clinical and Molecular Genetics, *Beverly S. Emanuel, Ph.D.*
– Roundtable discussion for professionals

G. Ask the Cardiologist, *William Mahle, M.D.*
– Q&A and discussion for professionals and parents

H. Teen Talk, *Alexandra Oppenheimer, Karen Ruckman Lindsay*
– Roundtable for teens only, led by two young women with VCFS

1:25 p.m. **Session Seven: Neural Imaging and Behavior**
Moderator: *Anne Marie Higgins, M.A., R.N., F.N.P.*
Brain Imaging, Development, Cognition and Memory in VCFS, *Stephan Eliez, M.D., P.D.*
Brain Structure, Connectivity and Cognitive Function in VCFS, *Tony J. Simon, Ph.D.*
Brain Imaging and Other Markers for Mental and Cognitive Function, *Wendy R. Kates, Ph.D.*
Cognitive and Behavioral Parameters Associated with VCFS, *Kevin M. Antshel, Ph.D.*
Behavioral and Psychological Issues Associated with VCFS and Their Implications, *Ann Swillen, Ph.D.*
Panel Discussion

3:20 p.m. Break

3:30 p.m. **Session Eight: Psychiatry**
Moderator: *Ann Swillen, Ph.D.*
Genetic, Developmental and Physical Factors Associated with Attention Deficit Hyperactivity Disorder in Patients with Velo-Cardio-Facial Syndrome
Doron Gothelf, M.D.
Genetic Correlates of Behavior in VCFS
Kieran C. Murphy, M.D., Ph.D.
Autism Spectrum Disorders Associated with 22q11 Deletions, *Marsha Gerdes, Ph.D.*
Psychiatric Disturbance in Adults with VCFS
Anne S. Bassett, M.D.
Reaction Panel: Questions from the Floor and Discussion
Kevin Antshel, Ph.D., Anne Bassett, M.D., Stephan Eliez, M.D., P.D., Doron Gothelf, M.D., William Graf, M.D., Wendy R. Kates, Ph.D., Kieran C. Murphy, M.D., Ph.D., Tony J. Simon, Ph.D., Ann Swillen, Ph.D.

5:30 p.m. Break

6 p.m. **Dinner** *(pre-registration and payment required)*
Emcee, *Julie Wootton*
"Footprints of Hope," *Raymond Tanner*
How to Succeed by Really Trying
Alexandra Oppenheimer
Concert emcee, *Julie Squair*
Piano Concert, *Karen Ruckman Lindsay*

Sunday July 25, 2004

7 a.m. **Continental breakfast with optional interactive breakout sessions**

(Register for sessions at check-in. Registration limited) These sessions offer an opportunity to ask questions and engage in topic-oriented discussions in a small group.

I. Sibling Relationships, *Solveig Oskarsdottir, M.D., April Elwood, C.C.L.S.*
– Designed for parents

J. Tips for Parents of Teens, *Donna Cutler-Landsman, B.S., M.S., Sharon Lynn Smith, M.Ed., Psy.D.*
– Workshop for parents, including a discussion about social skills

K. Support Groups, *Maureen Anderson*
– Facilitated discussion for parents

L. Coping with Behavioral and Psychiatric Issues with VCFS, *Stephan Eliez, M.D., Doron Gothelf, M.D.*
– Designed for professionals and parents

8:10 a.m. **Session Nine: Education and Living Skills**
Moderator: *Maureen Anderson*
Impact of VCFS on Learning and School Performance and What Can Be Done,
Donna Cutler-Landsman, B.S., M.S.
Voyage into Adulthood, *Sharon Smith, Med, Psy.D.*
Abstracts and Panel Discussion

Session 10: Cardiology
Moderator: *Angelo DiGeorge, M.D.*
Risk Factors for Cardiac Surgery, *Bruno Marino, M.D.*
Difference in Cardiovascular Outcomes in Patients with VCFS, *William T. Mahle, M.D.*
Approach to Screening for 22q/VCFS in Children with Heart Disease, *Elizabeth Goldmuntz, M.D.*
The Epidemiology of Deletion 22q11 in Congenital Heart Disease, *Lorenzo D. Botto, M.D.*
Abstracts and Questions

10:25 a.m. Break

10:35 a.m. **Session 11: Immunology, Medical Emergencies and Dentistry**
Moderator: *Lisa Kobrynski, M.D.*
Immunodeficiency in VCFS
Kathleen E. Sullivan, M.D., Ph.D.
Infections and Immunizations in Children with VCFS
Coleen K. Cunningham, M.D.
How to Prepare for Emergencies
Edward Stettner, M.D.
Oral and Dental Issues in VCFS
Gunilla Klingberg, D.D.S., Ph.D.
Dental Manifestations in VCFS
Jack E. Thomas Jr., D.D.S.
Abstracts
Questions and Discussion

1 p.m. Adjourn

Note: *This educational activity does not necessarily reflect the views, opinions, policies or procedures of Children's Healthcare of Atlanta, its staff or representatives. Children's cannot and does not assume any responsibility for the use, misuse or misapplication of any information provided. Concurrent sessions may be added to the conference agenda. Agenda is subject to change.*

GENERAL INFORMATION

The purpose of the three-day conference is to join VCFS researchers, practitioners and families from around the world for education on the latest discoveries and innovative treatments. The conference is also an opportunity to share experiences and provide management and support strategies. This is the 10th Annual International Conference of the Velocardiofacial Syndrome Educational Foundation, Inc., and the Fourth International 22q11.2 Deletion Conference. It is the first time the two groups have convened simultaneously.

OBJECTIVES

By the conclusion of the conference, participants will be able to:

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

ABOUT THE ORGANIZATIONS

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

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 3,000 people. 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 Syracuse (2005), France (2006) and Australia (also 2006) are underway. The Foundation membership is more than a 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 nonprofit 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 Web site.

The Fourth International 22q11.2 Deletion Conference is a bi-annual 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 Velo-Cardio-Facial 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.

Children's Healthcare of Atlanta, one of the leading pediatric healthcare systems in the country, is a 501(c)(3) not-for-profit organization that benefits from the generous philanthropic and volunteer support of our community and state. With 430 licensed beds in two hospitals and more than 400,000 annual patient visits, Children's is recognized for excellence in cardiac, cancer and transplant services, as well as in many other pediatric specialties. To learn more about Children's Healthcare of Atlanta, visit the Web site at www.choa.org or call 404-250-kids.

GENERAL INFORMATION

AUDIENCE

The target audience for this conference includes physicians, researchers, genetic counselors, speech–language pathologists, audiologists, regular and special education teachers, health educators, nurses, social workers, and other health professionals who provide care for people with the 22q11.2 deletion, as well as families interested in 22q11.2 deletion.

CONFERENCE LOCATION

The conference will be held at the Sheraton Midtown Atlanta Hotel at Colony Square at 188 14th Street NE, Atlanta, GA 30361. The hotel is within walking distance of the best shopping, restaurants and entertainment in the Southeast and just 15 minutes from Hartsfield-Jackson Atlanta International Airport. Guests can conveniently travel by Metropolitan Atlanta Rapid Transit Authority (MARTA) from the airport to the Arts Center Station, just a short walk from the hotel.

ACCOMMODATIONS

The hotel guestroom rate for this program is $95. To register, call the hotel reservation line 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 group rates cannot be guaranteed.

CONTINUING EDUCATION CREDIT

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Medical Association of Georgia through the joint sponsorship of Children's Healthcare of Atlanta, the Velo-Cardio-Facial Education Foundation, Inc., and the Fourth International 22q11.2 Deletion Conference.

Children's Healthcare of Atlanta is accredited by the **Medical Association of Georgia** to offer continuing medical education to physicians. Children's designates this educational activity for a maximum of 22.75 category 1 credits toward the **AMA Physician's Recognition Award**. Each physician should claim only those credits that he/she actually spent in the activity.

The AMA has determined that **non-US licensed physicians** who participate in this CME activity are eligible for AMA PRA category 1 credit.

The Georgia Speech-Language-Hearing Association is approved by the continuing education board of the **American Speech-Language-Hearing Association (ASHA)** to provide continuing education activities in speech-language pathology and audiology. This program is offered for 2.0 CEUs (Intermediate level; Professional area). ASHA CE provider approval does not imply endorsement of course content, specific products or clinical procedures.

This event is co-sponsored by the **American Counseling Association (ACA)**. ACA is approved by the National Board for Certified Counselors (NBCC), to offer **up to 23.0 contact clock hours** of continuing education credit. ACA adheres to NBCC continuing education guidelines. NBCC approved contact hours will be provided by ACA. ACA offers 10 contact clock hours for every (1) continuing education unit, as approved by the American Board of Genetic Counseling.

Children's Healthcare of Atlanta is an approved provider of continuing nursing education by the **Georgia Nurses Association**, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. 27.2 contact hours. Children's Healthcare of Atlanta recognizes that accreditation refers only to its continuing education activities and does not imply the American Nurses Credentialing Center's Commission on Accreditation approval or endorsement of any commercial products.

Children's Healthcare of Atlanta resolves to ensure that its educational mission and continuing medical education programs are not influenced by the special interests of any corporation or individual associated with its programs. While having a financial interest or professional affiliation with a corporation does not necessarily influence a speaker's presentation, the standards of the Accreditation Council for Continuing Medical Education require that this relationship be disclosed to the audience. Any potential conflict of interest will be made known to participants at the beginning of the program.

FAMILY MEETINGS WITH THE EXPERTS

The Velo-Cardio-Facial Syndrome Educational Foundation has offered free 10-minute clinics at past conferences. This year, the VCFSEF will again offer private family meetings with speech, feeding, education and foot pain experts. Interested families may sign up onsite beginning at registration Friday morning. Registration will be limited. For more information, contact Dr. Karen J. Golding-Kushner, Executive Director of the VCFSEF by e-mail at kgkushner@vcfsef.org or by phone at 1-866-VCFSEF5. Families arriving in Atlanta early who are interested in meeting with a speech expert on Thursday afternoon (July 22) may contact Dr. Golding-Kushner to make arrangements.

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Guest Pianist
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& Study of Velo-Cardio-Facial Syndrome
Director, Center for Genetic Communicative Disorders
University Hospital, Syracuse, New York
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CHILDCARE

Childcare is not provided by the conference sponsors. 22q Atlanta is providing an onsite 22q Atlanta Kids Camp for children ages birth through 16 years old. If interested in Kids Camp, please contact Monica Townsend-Mervin at mtownsend@peoplepc.com (preferred) or P.O. Box 29846 Atlanta, GA 30359. Pre-registration for Kids Camp is required by July 1.

SPECIAL NEEDS

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

ACKNOWLEDGMENTS

The Velo-Cardio-Facial Syndrome Education Foundation, Inc., the Fourth International 22q11.2 Deletion Conference and Children's Healthcare of Atlanta wish to acknowledge the following organizations for their generous support of the conference:

Centers For Disease Control and Prevention
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CONTACT INFORMATION

For registration information, contact the Children's Healthcare of Atlanta Continuing Education department at 404-785-7843 or e-mail continuing.ed@choa.org. To view an online brochure, visit the Children's Web site at www.choa.org/professionals/cme.

For more information about the Velo-Cardio-Facial Syndrome Educational Foundation, Inc., visit www.vcfsef.org.

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. does not act as an agent for any institution or professional member or any professional who is not a member of the Foundation but who may have an interest in treating individuals with VCFS.

Save the Date

17th Annual Cleft Lip and Palate Symposium
Sheraton Midtown Atlanta Hotel at Colony Square
July 22, 2004 • Atlanta, Georgia

The 17th Annual Children's Cleft Lip and Palate Symposium addresses the clinical and psychosocial needs of patients with cleft lip and palate and associated deformities. The goal is to achieve maximum physical, social and emotional functioning for patients.
The conference will provide information on the total care of children with cleft and craniofacial disorders, as well as recent technologies. Participants will learn about treatment perspectives, assessment procedures and outcomes. For more information, go to the Children's Healthcare of Atlanta Web site www.choa.org/professionals or e-mail continuing.ed@choa.org.

Children's
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1600 Tullie Circle
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The 10th Annual International Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc., and the Fourth International Conference for 22q11.2 Deletions

July 23-25, 2004
Atlanta, Georgia