

**17<sup>th</sup> Annual International Scientific Meeting**  
**July 16 - 18, 2010, Salt Lake City, Utah, USA**  
**The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.**  
**TENTATIVE PROGRAM: SUBJECT TO CHANGE**



The Utah 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. **See course information for number of ASHA CEUs, instructional level and content area.** ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.

**This program is offered for up to 1.9 ASHA CEUs (Intermediate level; Professional area)**

***Thursday, July 15, 2010***

**Registration: 4:00 – 7:00 PM**

**Welcome Reception: Pizza at the Pool (reservation required): 6:30 – 8:30 PM**

***Friday Morning, July 16, 2010***

Registration: Opens at 8:00

9:00 – 9:15: Opening Ceremonies and Introductions

*Karen J. Golding-Kushner (USA), Executive Director, VCFSEF*

*Steve Orton (UT, USA)*

*Becky Moretti (Lyman, WY, USA)*

**9:15 – 9:35: HONORED GUEST SPEAKER: Michael Leavitt, Governor of Utah (1993 – 2003) and Secretary of Health and Human Services (2005 – 2009).**

**9:35 – 9:55: KEYNOTE SPEAKER: John Opitz, M.D.**

Dr. Opitz is Professor of Pediatrics, Pathology, Human Genetics, and Obstetrics and Gynecology at the University of Utah Health Sciences Center in Salt Lake City. He is founder and former editor-in-chief of The American Journal of Medical Genetics. Dr. Opitz was a founding member of the American Board of Medical Genetics and the American College of Medical Genetics. He has authored over 500 peer-reviewed publications. He has delineated and described many new genetic syndromes, including Opitz syndrome, Smith-Lemli-Opitz syndrome and many others. He is a true legend in the field of human genetics, and we are honored to have him open our scientific program.

**Genotypes and Phenotypes**

9:55 – 10:15: Phenotype correlations in VCFS: a new method of analysis in a large sample of cases;  
*Marcia Friedman, Syracuse, NY; Alan Holland, Cork, Ireland; Nathaniel Miletta, Syracuse, NY; Anne Marie Higgins, Syracuse, NY; Bernice Morrow, Bronx, NY; Wendy Kates, Syracuse, NY; Robert J. Shprintzen, Syracuse, NY*

10:15 – 10:30: Can clustering analyses be used as a tool to identify sub types of people with the genetic disorder, velo-cardio-facial syndrome? *B. Sinderberry, S.U. Brown, P. Hammond, A. Stevens, D.G.M. Murphy, KC Murphy, L.E. Campbell, Newcastle, Australia*

- 10:30 – 10:45: Characterization of two extended families with VCFS: importance of extracardiac manifestations; *Alan Rope, K.A. Shoener, R. J. Hopkin, G. U. Andelfinger, D.W. Benson, Salt Lake City, UT*
- 10:45 – 10:55: Questions and Comments
- 10:55 – 11:10: Refreshments
- 11:10 – 11:30: Genetic modifiers of cardiac outflow tract anomalies in humans with VCFS; Tingwei Guo, Donna McDonald McGinn, Anna Blonska, Anne Bassett, Eva Chow, Mark Bowser, Molly Sheridan, Fritz Beemer, Koen Devriendt, M. Cristina Digilio, Bruno Marino, Bruno Dallapiccola, Courtney Carpenter, Anne Marie Higgins, Nicole Philip, Tony Simon, Karlene Coleman, Wendy Kates, Marcella Devoto, Elaine Zackai, Yuanyuan Shen, Zhe Liu, Jurg Ott, Robert Shprintzen, Beverly Emanuel, Bernice Morrow and the International Chromosome 22q11.2 Consortium
- 11:30 – 11:45: Phenotypic associations between major anomalies in a large cohort of people with VCFS; *Marcia Friedman, Syracuse, NY; Nathaniel Miletta, Anne Marie Higgins, Syracuse, NY; Bernice Morrow, Bronx, NY; Wendy Kates, Robert J. Shprintzen, Syracuse, NY*
- 11:45 – 11:55: Questions and Comments

### **Feeding Disorders and Treatments**

- 11:55 – 12:10: Transitioning from tube feedings to oral feedings; *Jill Merrow, M.A., Upstate Medical University, Syracuse, NY, USA*
- 12:10 – 12:25: When is reflux not reflux? *Jill Merrow, Upstate Medical University, Syracuse, NY, USA*
- 12:25 – 12:35: Questions and Comments

### **12:35 – 1:45: Lunch with the Experts**

Molecular and Clinical Genetics in VCFS; *Bernice Morrow, Alan Rope*  
 Diagnosis and management of feeding disorders in VCFS; *Jill Merrow*  
 Psychiatric and behavioral disorders in children; *Kevin Antshel; Bronwyn Glaser; Wendy Kates*  
 Medical management of VCFS; *Alan Shanske, Anne Marie Higgins*

Special Event: Lunch and Chat for Tweens and Younger Teens (11-15 years) *Dianne Altuna*

### **Speech Disorders and Their Treatments**

- 1:45 – 2:15: Oral Motor Treatment in Speech and Resonance Disorders: An Abiding Professional Issue; *Dennis Ruscello, Ph.D., West Virginia University, Morgantown, WV, USA*
- 2:15 – 2:30: The use of strategies for treating compensatory articulation errors in VCFS; *Antonio Ysunza, M.D., Sc.D., Hospital Gea Gonzales, Mexico City, Mexico*
- 2:30 – 2:45: From Sound Making to Meaningful Words; *Virginia Dixon-Wood, Gainesville, FL*
- 2:45 – 3:05: Video journey through speech therapy to normal articulation; *Karen J. Golding-Kushner, East Brunswick, NJ*
- 3:05 – 3:35: Panel Discussion: Why does my child sound just as bad as when speech therapy was started four years ago, and what am I supposed to do about it? *Dianne Altuna, Moderator; Karen J. Golding-Kushner, Cheryl Lozon, Dennis Ruscello; Antonio Ysunza; Virginia Dixon-Wood*
- 3:35 – 3:50: Questions and Comments
- 3:50 – 4:05: Refreshments
- 4:05 – 4:20: Cervical vascular and upper airway asymmetry in velo-cardio-facial syndrome: Correlation of nasopharyngoscopy with MRA; *Avi Oppenheimer, Bronx, NY; Susan Fulmer, Milwaukee, WI; Keivan Shifteh, Bronx, NY; Ja-Kwei Chang, Syracuse, NY; Allan Brook, Bronx, NY; Alan L. Shanske, Bronx, NY; Robert J. Shprintzen, Syracuse, NY*

- 4:20 – 4:40: Surgical outcomes in VCFS: Case reports demonstrating outcomes and methods of surgical planning and outcomes; Dianne Altuna, Dallas, TX; Virginia Dixon-Wood, Gainesville, FL; Robert J. Shprintzen, Syracuse, NY; Antonio Ysunza, Mexico City
- 4:40 – 4:55: Questions and Comments
- 4:55: VCFS Educational Foundation Members' Annual Business Meeting

**Friday night (time TBD): Annual Dinner for Everyone: reservations necessary (separate fee)**

***Saturday Morning, July 17, 2010***

- 8:00 – 9:00: Breakfast with the experts**  
 Regional Directors and Board Meeting (7:30 – 9:00)  
 Facebookers: Face-to-Face

**Reserve a table for your own group – let us know by 5:00 PM Friday**

**Development, Growth, Behavior, Social Skills, and Population Characteristics**

- 9:00 – 9:15: Mother-child interaction in children with VCFS; *Merav Burg-Malki, Ruth Feldman, Gil Disendurk, Rony Geva, Doron Gothelf, Tel Hashomer, Israel*
- 9:15 – 9:30: Social skills and bullying in schools; *Donna Cutler-Landsman, Middleton, WI*
- 9:30 – 9:55: Social functioning in VCFS: transition to adult life; *Kevin Antshel, Syracuse, NY*
- 9:55 – 10:05: Questions and Comments
- 10:05 – 10:30: Adults with VCFS: Challenges, Setbacks, and Victories; *Karen Ruckman- Lindsey; Poppy Anderson; Quinn Bradlee; Ariel Epstein; Judy Wickun; Raymond Tanner*
- 10:30 – 10:45: Refreshments
- 10:45 – 11:00: Autistic spectrum disorders in VCFS; *Carrie Bearden, Laurie Brenner, Jennifer Ho, Carolyn Chow, Maria Jalbrzikowski, Los Angeles, CA*
- 11:00 – 11:10: Anxiety, not intelligence, predicts adaptive functioning in children with VCFS; *Kathleen Angkustsiri, Ingrid Leckliter, Elliott A. Beaton, Joel Stoddard, Robin L. Hansen, Tony J. Simon, Sacramento, CA*
- 11:10 – 11:20: Children with VCFS report higher levels of anxiety but not depression compared with typically developing peers; *Elliott A. Beaton, Ingrid Leckliter, Kathleen Angkustsiri, Janice Enriquez, Tony J. Simon*
- 11:20 – 11:30: Attentional control throughout development in children with VCFS; *Heather M. Shapiro, Yukari Takarae, Danielle Harvey, Kathleen Angkustsiri, Tony J. Simon, Sacramento, CA*
- 11:30 – 11:40: Questions and Comments
- 11:40 – 11:50: Associations of behavioral and cognitive findings with physical findings in VCFS; *Nathanial Miletta, Syracuse, NY; Marcia Friedman, Syracuse, NY; Anne Marie Higgins, Syracuse, NY; Bernice Morrow, Bronx, NY; Wendy Kates, Syracuse, NY; Robert J. Shprintzen, Syracuse, NY*
- 11:50 – 12:05: The time has come: the critical need for a registry for VCFS; *Vandana Shashi, Durham, NC*
- 12:05 – 12:20: Linear growth and weight gain in VCFS: what the new growth charts mean; *Robert J. Shprintzen, Syracuse, NY*
- 12:20 – 12:30: Questions and Comments

**12:30 – 2:30: Lunch with the Experts and Discussion Sessions (Extended sessions)**

Treatment of Speech and Hypernasality in pre-school and school-age children (speech and surgery); *Karen Golding-Kushner, Dennis Ruscello; Tony Ysunza*

Genomic roundtable: This session is open to anyone involved in or interested in genomic research involving VCFS

Educational Issues-Focus on Academics; *Donna Landsman, M.S.*

Special Events:

Luncheon for Adults and Teens with VCFS; *Karen Ruckman-Lindsey*

Luncheon for parents of adults, teens, and tweens with VCFS – a chance to talk;  
*Roger Ruckman*

***Saturday afternoon***

2:30 – 2:50: Longitudinal changes in neuroanatomy and association with psychiatric symptoms; *Wendy Kates, Syracuse, NY*

2:50 – 3:05: Genetic Markers Linked to Differences in Brain Development in VCFS; *Ioana Coman, Petya Radoeva, Frank Middleton, Syracuse, NY, Bernice Morrow, Bronx, NY, Wendy Kates, Syracuse, NY*

3:05 – 3:15: A clinical trial for the treatment of psychiatric disorders in VCFS: moving from the lab to the patient; *Robert J. Shprintzen, Anne Marie Higgins, James Megna, Kevin Antshel, Frank Middleton, Wendy Kates, Syracuse, NY*

3:15 – 3:30: Questions and Discussion

3:30 – 3:45: Refreshments

3:45 – 4:15: Cognitive Impairments in Children with VCFS: Some Explanations and Prospects for Intervention; *Tony Simon, Sacramento, CA*

4:15 – 4:45: A socio-emotional remediation program for individuals with velo-cardio-facial syndrome; *Bronwyn Glaser, Danny Dukes, Catherine Pasca, Sonia Martinez, Mélanie Chabloz, Stephan Eliez Geneva, Switzerland*

4:45 – 5:00: Questions and Comments

***Sunday Morning, July 18, 2006***

**8:00 – 9:00: Breakfast with the experts**

Social skills; *Kevin Antshel, Merav Burg, Bronwyn Glaser*

Early Intervention: guiding speech development from birth to 3 years; *Virginia Dixon-Wood; Dianne Altuna; Jill Merrow*

Cognitive and learning disorders in VCFS and their management; *Wendy Kates, Tony Simon; Bronwyn Glaser*

Cardiology; *Roger Ruckman*

9:00 – 9:30: Supporting parents of children with disabilities across the lifespan; *Nancy Murphy, Salt Lake City, Utah*

9:30 – 9:40: Questions and Comments

9:40 – 10:00: Individualized Education Plans (IEPs): How to get things done and how to use health care providers in the process; *Cristina Bush, Other Presenters TBA*

10:00 – 10:15: Questions and Comments

10:15 – 11:00: Refreshments

- 11:00 – 11:30: Speech therapy in the schools: can school-based clinicians get good results in children with rare medical conditions like VCFS? *Dennis Ruscello, Morgantown, West Virginia*
- 11:30 – 11:45: International Initiatives: The Continuing Growth of the Educational Foundation; *Regional Directors of the VCFSEF including Dianne Altuna, Merav Burg (representing Doron Gothelf), Linda Campbell, Bronwyn Glaser, Toko Hayakawa (representing Nagato Natsume), and Antonio Ysunza*
- 11:45 – 11:55: VCFS and the 22q11 Foundation in Australia; *Maria Kamper, Willoughby, New South Wales, Australia*
- 11:55 – 12:00: Conclusion and announcements for next year's meeting; *Karen J. Golding-Kushner, Ph.D., Executive Director*

## FACULTY

Dianne Altuna, M.S.  
VCFSEF Regional Director, North America  
Fogelson Plastic Surgery Center, Childrens Medical Center  
Lecturer, Univ. of Texas at Dallas, Dallas, TX, USA

Poppy Anderson

Kathleen Angkustsiri, M.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Kevin M. Antshel, Ph.D.  
Department of Psychiatry and Behavioral Science  
Upstate Medical University, Syracuse, NY, USA

Carrie Bearden, Ph.D.  
Semel Institute for Neuroscience and Human Behavior  
UCLA, Los Angeles, CA, USA

Elliott A. Beaton, Ph.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Quinn Bradlee, Washington, D.C., USA

Laurie Brenner, M.A.  
Department of Psychology, UCLA, Los Angeles, CA, USA

Allan Brook, M.D.,  
Dept of Radiology, Montefiore Medical Ctr, Bronx, NY, USA

S.U. Brown, University of Newcastle, Newcastle, NSW, Australia

Merav Burg-Malki, Ph.D.  
Chaim Sheba Medical Center and Bar Ilan University  
Tel Hashomer, Israel

Cristina Bush  
Membership Chair, VCFS Educational Foundation  
Warren, New Jersey

Linda E. Campbell, Ph.D.  
University of Newcastle, Newcastle, NSW, Australia

Mélanie Chablotz, Research Unit, Department of Psychiatry  
University of Geneva, Geneva, Switzerland

Ja-Kwei Chang, M.D., Department of Radiology  
Upstate Medical University, Syracuse, NY, USA

Carolyn Chow  
Semel Institute for Neuroscience and Human Behavior, UCLA  
Los Angeles, CA, USA

Ioana Coman, Ph.D.  
Dept of Psychiatry and Behavioral Sciences,  
Upstate Medical University, Syracuse, NY, USA

Donna Cutler-Landsman, M.S.  
Middleton-Cross Plains Area School District, Middleton, WI, USA

Gil Disendurk  
Sheba Medical Center and Bar Ilan University, Tel Hashomer, Israel

Virginia L. Dixon-Wood, M.A.  
University of Florida, Gainesville, FL, USA

Danny Dukes, Research Unit, Department of Psychiatry  
University of Geneva, Geneva, Switzerland

Stephan Eliez, M.D., VCFSEF Regional Director, Europe  
Professor of Psychiatry, University of Geneva School of Medicine  
Geneva, Switzerland

Janice Enriquez, Ph.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Ariel Epstein, California, USA

Ruth Feldman, Sheba Medical Center and Bar Ilan University  
Tel Hashomer, Israel

Marcia Friedman, VCFS International Center  
Upstate Medical University, Syracuse, NY, USA

Susan Fulmer, M.D., Department of Otolaryngology  
Medical College of Wisconsin, Milwaukee, WI, USA

Rony Geva, Sheba Medical Center and Bar Ilan University  
Tel Hashomer, Israel

Bronwyn Glaser, Ph.D.  
Research Unit, Department of Psychiatry  
University of Geneva, Geneva, Switzerland

Karen J. Golding-Kushner, Ph.D.  
Executive Director, VCFS Educational Foundation  
Private Practice, Speech Pathology, East Brunswick, NJ, USA

Doron Gothelf, M.D., Regional Director, Middle East, VCFSEF  
Sheba Medical Center and Bar Ilan University, Tel Hashomer, Israel

Peter Hammond, University College, London, United Kingdom

Toko Hayakawa, Speech Pathologist

Robin L. Hansen, M.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Danielle Harvey, Department of Biostatistics, UC Davis, Davis, CA

Anne Marie Higgins, R.N., F.N.P., M.A.  
VCFS International Center  
Upstate Medical University, Syracuse, NY, USA

Jennifer Ho, Semel Institute for Neuroscience and Human Behavior  
UCLA, Los Angeles, CA, USA

Alan Holland, Ph.D.  
Cork Constraint Computation Centre  
Dept. of Computer Science, University College Cork, Cork, Ireland

Maria Jalbrzikowski, M.A.  
Department of Psychology, UCLA, Los Angeles, CA, USA

Maria Kamper, President, VCFS and 22q11 Foundation Australia  
Willoughby, New South Wales, Australia

Wendy Kates, Ph.D.  
Department of Psychiatry and Behavioral Science  
VCFS International Center  
Upstate Medical University, Syracuse, NY, USA

Ingrid Leckliter, Ph.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Xiobo Li, Ph.D.  
Albert Einstein College of Medicine, Bronx, NY, USA

Cheryl Lozon, M.A., Ferndale, MI, USA

Sonia Martinez, Research Unit, Department of Psychiatry  
University of Geneva, Geneva, Switzerland

James Megna, M.D., Ph.D.  
Department of Psychiatry and Behavioral Science  
Upstate Medical University, Syracuse, NY, USA

Jill Merrow, M.A., Director  
Ctr for Children's Feeding and Swallowing Disorders  
Upstate Medical University, Syracuse, NY, USA

Frank Middleton, Ph.D.  
Department of Neuroscience  
Upstate Medical University, Syracuse, NY, USA

Nathanial Miletta, VCFS International Center  
Upstate Medical University, Syracuse, NY, USA

Becky Moretti, Lyman, Wyoming, USA

Bernice Morrow, Ph.D.  
Department of Molecular Genetics  
Albert Einstein College of Medicine, Bronx, NY, USA

D.G.M. Murphy, Kings College, Institute of Psychiatry, London, UK

Kieran Murphy, M.D., Royal College of Surgeons, Dublin, Ireland

Nancy Murphy, M.D., Associate Professor of Pediatrics  
University of Utah, Salt Lake City, UT, USA

Nagato Natsume

Avi Oppenheimer, M.D., Department of Radiology  
Montefiore Medical Center, Bronx, NY, USA

Steven Orton, President, VCFS Educational Foundation, Inc.  
Payson, UT, USA

Catherine Pasca, M.A., Research Unit, Department of Psychiatry  
University of Geneva, Geneva, Switzerland

Karen Ruckman- Lindsey, Braintree, MA, USA

Roger Ruckman, M.D.  
Children's National Medical Center, Washington, D.C., USA

Dennis Ruscello, Ph.D., Professor  
Dept. of Communication Disorders  
West Virginia University, Morgantown, WV, USA

Alan L. Shanske, M.D.  
Albert Einstein College of Medicine, Bronx, NY, USA

Heather M. Shapiro  
Department of Psychiatry and Behavioral Sciences,  
M.I.N.D. Institute, Sacramento, CA  
UC Davis Medical Center, Sacramento, CA, USA

Vandana Shashi, M.D.  
Duke University Medical Center, Durham, NC, USA

Keivan Shifteh, M.D., Department of Radiology  
Montefiore Medical Center, Bronx, NY, USA

Robert J. Shprintzen, Ph.D., VCFS International Center  
Upstate Medical University, Syracuse, NY, USA

Tony J. Simon, Ph.D.  
University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

B. Sinderberry, University of Newcastle, Newcastle, NSW, Australia

A. Stevens, Kings College, Institute of Psychiatry, London, UK

Joel Stoddard, M.D., University of California, Davis Medical Center  
M.I.N.D. Institute, Sacramento, CA, USA

Yukari Takarae, Center for Mind and Brain, UC Davis, Davis, CA

Raymond Tanner, Adelaide, Australia

Judy Wickun, Ricklin, CA, USA

Antonio Ysunza, M.D.  
Hospital Gea Gonzales, Mexico City, Mexico