

July 2010

Volume 16, Issue 3

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Sheraton, Salt Lake City, Utah, location of the VCFSEF 17th Annual International Scientific Meeting. July 16-18, 2010

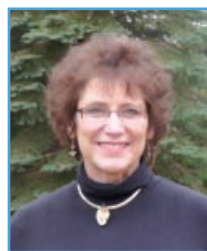
## Important News

### 17th Annual International Scientific Meeting

Sheraton Salt Lake City Hotel  
Salt Lake City, Utah  
July 16-18, 2010

Visit our [website](#) for more information, hotel and conference registration, and forms to submit abstracts or program suggestions, and to participate in a talent showcase.

## GREETINGS FROM THE EDITOR



Sue Carneol, MS,  
CCC-SLP

I hope this newsletter finds you in good spirits. This summer edition is brief to give all of us more quality time with family and friends while the sun is shining and the weather is good. While your summer vacation may include small day trips an outdoor adventure, exotic excursions, or just good old R& R, we hope your plans include our annual International Scientific meeting in Salt Lake City July 15-18, 2010. As you will see in this newsletter, the program is packed with state of the art information and cutting edge research findings, highlighted by presentations by internationally acclaimed faculty. It is not too late to register. There will be plenty of fun, networking, and learning opportunities for the entire family and professionals, alike. Read on for the details.

Hope to see you in sunny Salt Lake City!

- Sue Carneol, MS, CCC-SLP  
VCFSEF Editor



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## MESSAGE FROM THE EXECUTIVE DIRECTOR



*Karen Golding-Kushner,  
Ph.D.*

**A**utism. Anxiety. Adulthood.  
**B**rain. Behavior. Bullying.  
**C**ognition. Communication.  
**D**evelopment.  
**E**ducation.  
**F**eeding.  
**G**rowth. Genetics.



*John Opitz, MD*



*Dennis Ruscello, PhD*

Well, you get the idea. These are just a few of the topics from A to Z that will be discussed at the 17th Annual International Scientific Meeting of the VCFS Educational Foundation next month. They are not only being discussed. We will be privileged to learn about these issues from the international experts who are making breakthroughs in our understanding of how these issues are affected by the 22q11.2 deletion and who are blazing new trails in effective treatment. John Opitz, MD and Dennis Ruscello, PhD are two of our guest faculty this year. Dr. Opitz, who will be our Keynote speaker, is a world-renowned geneticist at the University of Utah Health Sciences Center in Salt Lake City. Dr. Ruscello is Professor of Speech Pathology at West Virginia University, where he is Co-Director of the Cleft Palate Team. He has published extensively on the treatment of compensatory speech problems in cleft palate, and on oral-motor therapy. A copy of the program is included in this newsletter. Take a peak and see all the topics to be covered.

The program committee is working diligently to be sure there is ample time for questions and discussion. We are still working out details of the popular Breakfasts and Lunches with the Experts, and if there is a topic you would like to suggest for these informal round-table discussions, please let me know right away.

People from every continent are already registered – North America, South America, Europe, Asia, Africa, Australia. (Ok, nobody from Antarctica.) Faculty are already sending us their handouts so we can put everything together. The local arrangements committee is finalizing plans for Kids Zone, and we have a list of performers from among our own members and faculty who will dazzle you at the optional dinner on Friday night. You won't want to miss it!

Hope to see you all in Salt Lake City!

*- Karen J. Golding-Kushner, Ph.D.  
Executive Director*

## WELCOME FROM THE PRESIDENT

### Getting the Most out of the 2010 Conference Steve's Column to Fellow VCFS Parents



*Steve Orton, President*

The first step in getting the most out of the conference is to attend. Four years ago, I was like many parents who wondered how our family could attend the conference. We decided just a few weeks before the conference to see if it was possible. I found a good price on a flight and made the arrangements to attend the conference in Plano. I am very grateful that I made that trip to hear the latest in the research, to make friends, to meet with the experts, and to learn so much more about VCFS. As a family, we just didn't have the funds to send all of us, so I purchased the audio recordings of the conference so my wife could hear the information as well.

The next year our family made a vacation trip to include the conference in Troy, Michigan. We were able to visit with family in Illinois and in Michigan before the conference. We were very surprised that the conference was in Troy, because we have family there. Our sister-in-law was one of the main volunteers that attended the conference everyday to help with Child Care. We are grateful that she invested the time and some resources to help with the conference. Giving of your time and resources to help with the conference makes it better for everybody. We really appreciated talking to other families and learning of their challenges and approaches. Share your knowledge, resources, and skills.

## Welcome from the President

*(Continued from page 2)*

At the conference in Troy, I gained a respect for the experts. It is wonderful to see how the researchers, doctors, and technicians spend their working hours in improving the VCFS world; however the experts I learned to appreciate at the conference are the parents. I believe a mom, in particular, has a keen sense of the needs of her child. Moms know best ... and I know that because my mom told me so. When moms take their understanding of their VCFS child and compile it with the knowledge of expertise gathered at the conference they become the greatest experts for their child.

In 2009, my wife and I had saved all of our frequent-flier miles to use for the conference in Italy. We enjoyed the entire conference combined with a short European vacation. Bellissimo! We made friends from all over the world, such as Sweden, Norway, Denmark, England, Japan, Switzerland, Mexico, Australia, Israel, Belgium, Ireland, France, and of course Italy. It was interesting to see how the cultures managed the challenges of VCFS.

Here is my list on getting the most out of the conference.

1. Come to the conference. If you don't come, you can't fully benefit. However, if your circumstances prohibit you from coming, gather your local support group (or start one) and have the group sponsor a family or an individual.
2. Go to the sessions. The information from the session is usually more than I can comprehend, but I build on what I understand and review the conference afterwards.
3. Share your knowledge. Your experiences can enrich and help the lives of others.
4. Share your resources. If you have something that will help the lives of the VCFS community, share it.
5. Be a friend. The conference is full of parents who need to talk and need some advice.
6. Learn that you are not alone. Without the support of fellow VCFS families you will likely feel that you are alone in your challenges.
7. Realize your investment. The conference and the banquet can be considered pricey when compared to a value meal at a fast-food restaurant, but with the conference you can get quality time with a fellow parent or expert. The hotel gives us a complete environment where we can meet and exchange ideas and learn from the experts.
8. See something local. If you make the trip to the conference, carve some time to see or do something in the area.
9. Take time to relax. You can't enjoy the conference if you are strung too tight. Enjoy the pool, take a nap, read a book, or do something that lets you be calm and collected.
10. Follow-up. Read your notes and create an action plan. Stay connected with the friends you meet.

~Steve Orton  
VCFSEF President

## DO YOU FACEBOOK?



Over 700 people have joined our group, The VCFS Educational Foundation on Facebook. There are active discussions on a variety of subjects, ranging from potty training to issues affecting adults with VCFS. Group members are from all over the world – Malaysia, Japan, Australia, Ireland, UK, Croatia, Chile, Mexico, Canada, the US and many other places. We've got relatives of people with VCFS, people with VCFS, and many professionals who are on there responding to questions and taking part in lively discussions. We invite you all to join!

We are working on details for something special for "VCFSEF Facebookers" at our meeting in SLC. We used to say it would be nice to put a face to a name. These days, we've seen each others faces (and even lots of pictures of members of the family, especially some of the cutest children on earth - check out the photo gallery!!!) so let's just say that in SLC, we are planning some type of get together so we can put real people to the little profile pictures!

This is an open invitation to join our Facebook group. Just remember, being a member of the FB group does NOT automatically make you a member of the VCFS Educational Foundation. To join the EF, that's us, the group publishing this newsletter and sponsoring the meeting in Salt Lake, go to our website at [www.vcfsef.org](http://www.vcfsef.org) and complete the membership application, That's all there is to it. This will also give you access to our members-only features such as power point presentations from past conferences. Dues are VERY low, but can be waived if payment would present a hardship, so please do not hesitate to check us out.

See you online.

# VCFSEF 17TH ANNUAL INTERNATIONAL SCIENTIFIC MEETING

## TENTATIVE PROGRAM: SUBJECT TO CHANGE

July 16 - 18, 2010, Salt Lake City, Utah, USA



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 CEU's instructional level and content area. ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.

**This course is offered for 19 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: 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

9:35 – 9:50: Phenotype correlations in VCFS: a new method of analysis in a large sample of cases; *Marcia Friedman, Syracuse, NY; Alan Holland, Cork, Ireland; Nathaniel Mileta, Syracuse, NY; Anne Marie Higgins, Syracuse, NY; Bernice Morrow, Bronx, NY; Wendy Kates, Syracuse, NY; Robert J. Shprintzen, Syracuse, NY*

9:50 – 10:05: 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*

10:05 – 10:20: Characterization of two extended families with VCFS: importance of extracardiac manifestations; *Alan Rope, K.A. Shooner, R. J. Hopkin, G. U. Andelfinger, D.W. Benson, Salt Lake City, UT*

10:20 – 10:30: Questions and Comments

10:30 – 10:45: Refreshments

### 10:45 – 11:05: Honored Guest Speaker: Michael Leavitt, Governor of Utah (1993 – 2003) and Secretary of Health and Human Services (2005 – 2009).

11:05 – 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,*

## International Scientific Meeting Tentative Schedule

(Continued from page 4)

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*

## Online Registration

### Meeting Registration

**17th Annual International Scientific Meeting  
 July 16-18, 2010  
 Salt Lake City, Utah**

[http://www.vcfsef.org/conference\\_registration/2010\\_slc/slc\\_1.html](http://www.vcfsef.org/conference_registration/2010_slc/slc_1.html)

### Hotel Information

The **Sheraton Salt Lake City Hotel** is ready to take your reservations for the 17th Annual International Scientific Meeting of the VCFSEF.

**We have negotiated a very low rate of \$99 per night, but you must reserve through this link and be part of our room block to get that rate.** The rate is available for reservations made by July 12, but rooms are subject to availability, so do not delay!

[Click Here for Hotel Reservations.](#)

## International Scientific Meeting Tentative Schedule

(Continued from page 5)

- 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; *Nathaniel 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 – 12:15: Linear growth and weight gain in VCFS: what the new growth charts mean; *Robert J. Shprintzen, Syracuse, NY*
- 12:15 – 12:25: Questions and Comments
- 12:25 – 2:15: 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

### Saturday afternoon

- 2:15 – 2:30: Language pathway abnormalities in schizophrenia and high-risk people; *Xiobo Li, Bronx, NY*
- 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*

Continued on page 7

## International Scientific Meeting Tentative Schedule

(Continued from page 6)

- 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*
- 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*

### INTERNATIONAL SCIENTIFIC MEETING 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

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

## International Scientific Meeting Faculty

(Continued from page 7)

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Gil Disendurk

Sheba Medical Center and Bar Ilan University

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Regional Director, Middle East, VCFSEF  
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Peter Hammond

University College, London, United Kingdom

Toko Hayakawa

Speech Pathologist

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Jennifer Ho

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Cork Constraint Computation Centre  
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University College Cork, Cork, Ireland

Maria Jalbrzikowski, M.A.

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Maria Kamper

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

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

## International Scientific Meeting Faculty

(Continued from page 8)

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M.I.N.D. Institute, Sacramento, CA, USA

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Becky Moretti

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Kings College, Institute of Psychiatry, London, UK

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Nagato Natsume

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Karen Ruckman- Lindsey

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B. Sinderberry,

University of Newcastle, Newcastle, NSW, Australia

A. Stevens

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Joel Stoddard, M.D.

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Yukari Takarae

Center for Mind and Brain, UC Davis, Davis, CA, USA  
Raymond Tanner, Adelaide, Australia  
Judy Wickun, Ricklin, CA, USA

Antonio Ysunza, M.D.

Hospital Gea Gonzales, Mexico City, Mexico

## RESEARCH ROUND-UP

### A Double Blind Placebo Controlled Clinical Trial for the Treatment of Psychosis in Individuals with Velo-Cardio-Facial Syndrome

Individuals who have velo-cardio-facial syndrome (also known as VCFS, 22q11 deletion syndrome, DiGeorge syndrome, and Shprintzen syndrome) and who are currently experiencing psychiatric illness including schizophrenia, bipolar psychosis, schizoaffective disorder, mood disorder with psychotic features, or psychosis NOS may be candidates for a clinical trial at Upstate Medical University in Syracuse, NY that is designed to assess the safety and effectiveness of an FDA approved drug for the treatment of their psychosis. Study subjects must be between 16 and 65 years of age and have an IQ score of at least 50. There are several other qualifications for the study that will be explained in detail for those interested in participating. For details about qualifications for the study, please contact the study's principal investigator, Dr. Robert Shprintzen, or the study coordinator, Anne Marie Higgins, R.N., F.N.P., M.A. by telephone at 315-464-6590, 315-464-6597, 315-464-6595, by fax at 315-464-6598, or by email at [vcfs@upstate.edu](mailto:vcfs@upstate.edu).

## REGIONAL UPDATES



### Latin America

Antonio Ysunza, MD,  
SciD  
VCFSEF Regional  
Director Latin America

There are quite a few things to report from Latin America. I do not know how many of you are familiar with Bolivia. It is a relatively

small country in comparison to other South American countries like Brazil or Argentina. Bolivia has a total population of nine million. About 60% of the population is full blooded native Indian, basically from two tribes, the Quechua and the Aymara. The current president of Bolivia, Mr. Evo Morales, is from the Aymara tribe. You may know more about Bolivia than you think. Perhaps some of you remember the great movie "Butch Cassidy and the Sundance Kid". It starred Paul Newman and Robert Redford and told the true story of two American bank robbers who took their "trade" to Bolivia. They were finally killed by the Bolivian Army at the end of the 19th century. Another historic fact about Bolivia is that the famous guerilla fighter, Ernesto "Che" Guevara was captured and executed near Cochabamba in the 1960's.

*Antonio Ysunza, MD, SciD  
VCFSEF Regional  
Director Latin America*

The most recent interesting fact about Bolivia is that in March 2010, a group of families from the beautiful city of Cochabamba in Bolivia, invited yours truly to a conference on Velo-Cardio-Facial Syndrome (VCFS). The conference was a great success and had a wide range of participants. There were some who had confirmed diagnoses of the 22q11 deletion. Others attended the conference with their families because they had a history of cleft palate, but had not been diagnosed with the syndrome, and others had endured what a lot of the families all over the world have endured. That is, being treated by different medical specialists without a final diagnosis. Among the conference attendees were a variety of professionals including speech pathologists, plastic surgeons, otolaryngologists, dentists and pediatricians. Thanks to this meeting, over 700 brochures in Spanish will be distributed among professionals all over Bolivia. I would like to especially thank the Pavisic family from Cochabamba for arranging this conference which was so beneficial to many families and professionals all over Bolivia. The Pavisic family organized a fundraiser that yielded 400 US dollars for the Foundation.

The other fortunate news from Latin America comes from the south of Chile, where the

devastating earthquake took place. The families from the VCFS support group in Santiago are safe and sound. Moreover, despite this natural disaster, the group from Santiago de Chile will host a huge scientific meeting focusing on VCFS in August of this year. Dr. Sherard Tatum from Syracuse, New York will present and possibly perform some surgeries, assisted by local surgeons. The group of families and professionals from Santiago de Chile has been working on this meeting for more than a year and I am sure it will be a great success. Several surgeons, speech pathologists, pediatricians, geneticists, and professionals from other related branches from South America will attend. Once again, the VCFSEF Spanish brochures will be an excellent resource for those attending the conference.

There is increased awareness of VCFS in Latin America based on all the emails I have been receiving from Bolivia, Chile, and Brazil. I have even conducted conferences via Skype with some families. I would like to point out that I do not speak Portuguese, but we have been able to communicate efficiently in "Portognol" a combination of Spanish and Portuguese. Well, that is all for now. Saludos a todos desde Latinoamérica !!!!

## Regional Updates

(Continued from page 10)



*Bronwyn Glaser, Ph.D.  
Co-Regional Director,  
EuropeVCFSEF*

### Europe

Bronwyn Glaser, Ph.D.  
Co-Regional Director,  
Europe VCFSEF  
europe@vcfsef.org

Greetings and salutations from the EU (and non-EU)! It is looking like another hot summer over here, and things are also heating up for our national associations. We have recent reports from the presidents of Ireland and Italy.



*Stephan Eliez, M.D.  
Co-Regional Director,  
EuropeVCFSEF*

Here's the latest scoop from the Emerald Isle: Irish President Anne Lawlor wrote to let us know that

www.eurodis.org is an excellent address for finding out about the European Reference Network and Centers of Expertise. The overall goal of the network is to identify as many centers as possible that are qualified for treating rare diseases, so that all families have access to good care. In the case that a center of expertise is located in a nearby country, such a network facilitates the transfers of patients across national boundaries. This is an excellent example of the way the EU can help families in such situations. In addition, 22Q Ireland

is gearing up for their annual conference day on June 19th. They will be spending time on educational issues with guest speaker Donna Cutler-Landsman, a teacher, book author, and educational consultant, Lindsey and Harrison Stedman, parents who have home-schooled their affected child, and Grania Clarke, director of St Michael's House, the biggest provider of community-based services for children with intellectual disabilities in Ireland.

We also heard from Giulietta Cafiero down in our favorite Boot! President Cafiero let us know that Aldel22 has had a busy year as well. They finished a publication for families and doctors in collaboration with an Italian association working on early immunodeficiency disorders (A.I.P.). It is an informative publication using results based on work done in Italian clinical centers with children with deletion 22q11. Similar to President Lawlor's news, this is another interesting way of passing medical protocols and treatment ideas between centers and regions. Aldel22 has also given scholarships to one psychiatrist and two psychologists who will be conducting a study on children ages 4-18 at the Careggi Hospital of Florence. In addition, Aldel22 led a course for the heads of the 15 regional Italian associations to maximize the groups' productivity and communication.

We are pleased to see so many of our European members setting such ambitious agendas for themselves. Not only are they changing legislation and practice in their own countries, but they are also making a huge impact on VCFS care in all of Europe!



*Dianne Altuna  
US/Canada Regional  
Director*

### US/Canada

Dianne Altuna  
US/Canada Regional  
Director

The Colorado General Assembly has proclaimed the week of August 22-28, 2010 to be "22q11.2 Deletion Syndrome Awareness Week."

The Wisconsin VCFS Family Network and Children's Hospital of Wisconsin hosted a wonderful event in May to celebrate the establishment of an endowment fund which will promote public awareness of VCFS, research and continuing education for professionals. Quinn Bradlee, author of *A Different Life; Growing up with Learning Disabilities and Other Adventures*, was the guest speaker who addressed the multigenerational audience from Wisconsin, Illinois, Iowa and Minnesota. The event provided a springboard for a new Facebook group for those in the Midwest/Great Lakes Region. You are now invited to join the "Velo-Cardio-Facial Syndrome-Wisconsin Parent Group".

There are many exciting social, educational and networking opportunities occurring all over the US and Canada. Please keep Dianne posted on all the "happenings" by emailing her at [uscanada@vcfsef.org](mailto:uscanada@vcfsef.org)

## Save The Dates

July 16-18, 2010 Salt Lake City, Utah, USA

July 2011 New Jersey, USA

July 2012 Pittsburgh, Pennsylvania, USA

July 2013 Dublin, Ireland

## DONOR HONOR ROLL / JANUARY-MARCH 2010

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*In support of the 17th Annual International Scientific Meeting of the VCFS Educational Foundation*

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*Editor's note: We want to thank all of our generous donors for their support of the VCFSEF which relies on membership dues and donations for its funding.*

# VCFSEF DONATION FORM

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc is an organization comprised of both professionals and lay people. It's mission is to educate the public, the scientific community, families and individuals affected by Velo-Cardio-Facial Syndrome (VCFS). Also known as DiGeorge & 22q.11.2 deletion, VCFS is one of the most common genetic syndromes.

Your donation helps support the Foundation's mission and is greatly appreciated. **You may also make a donation online at: [http://www.vcfsef.org/support\\_foundation/donations.html](http://www.vcfsef.org/support_foundation/donations.html)**

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VCFSEF, Inc is a US 501(c)(3) non-profit organization. Donations are US tax-deductible to the fullest extent of the law.

**Please consider a donation to support our efforts:**

## STEP 1: Donation Amount

- President's Circle \$5,000+** \$ \_\_\_\_\_
- Founder's Circle \$1,000**
- Benefactor \$500**
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## STEP 3: Enter Name (if applicable)

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- General Donation**  
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- Provides scholarships for the VCFSEF annual meeting
- Tony Lipson Memorial Fund**  
- Helps members from Australia to attend the VCFSEF annual meetings
- Amanda McPherson Fund**  
- Supports layout, printing, and distribution of informational brochures in multiple languages
- Kid's Zone Fund**  
- Supports childcare and children's activities for children with VCFS and their siblings during the Annual International Scientific Meeting so that professionals with children and parents may attend sessions.

Please include this completed form with your payment made payable to:

**VCFS Educational Foundation, Inc.**  
**P.O. Box 874**  
**Milltown, NJ 08850**

**Total Enclosed \$** \_\_\_\_\_



## VCFSEF MERCHANDISE & "KNOWLEDGE IS HOPE" BROCHURE

### Knowledge Is Hope Bracelets

Promote VCFS awareness by purchasing "Knowledge is Hope" wristbands, available in Adult size (8 1/4") and Child size (7 1/4"). The wristbands are made of 100% silicone and read **KNOWLEDGE IS HOPE** on the outside of the band, with [www.vcfsef.org](http://www.vcfsef.org) on the inside.

**Each wristband is \$1.50 US and shipping is FREE!!!** Due to shipping costs, we suggest a minimum order of 5 wristbands for international purchases.

You can purchase your bracelets directly from the foundation's web site at [http://www.vcfsef.org/products/product\\_list.php](http://www.vcfsef.org/products/product_list.php)

For questions regarding wrist bands, contact [wristbands@vcfsef.org](mailto:wristbands@vcfsef.org).



### Educational Foundation Logo Tee-Shirts

Promote VCFS awareness by purchasing "Knowledge is Hope" tee-shirts, available in youth sizes S, M, L and adult sizes S, M, L, XL, XXL, XXXL.

The tee-shirts are white and made of 100% cotton, and read **KNOWLEDGE IS HOPE**, above the VCFSEF logo.

You can purchase your tee-shirts directly from the foundation's web site at [http://www.vcfsef.org/products/product\\_list.php](http://www.vcfsef.org/products/product_list.php). Each tee-shirt is \$15 .00 US, with free shipping in the U.S. and Canada. For orders of 4 or more, shipping outside the U.S. and Canada is also free.

For questions regarding tee shirts, including shipping cost to other destinations, contact [tshirts@vcfsef.org](mailto:tshirts@vcfsef.org).

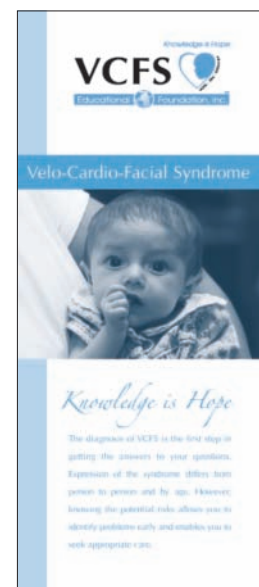


### Knowledge is Hope brochure

The "Knowledge is Hope ©" brochure published by the VCFS Educational Foundation, Inc is an 18 page booklet that contains basic information about velo-cardio-facial syndrome for providers, families and others interested in learning more about VCFS. It provides an essential overview about the syndrome to facilitate proper diagnosis and treatment. Order copies for you patients or care providers. You can order brochures directly from the foundation's web site at: <http://www.vcfsef.org/brochures/index.php>.

**The Knowledge is Hope brochure is currently available in the following languages:**

- English
- French
- Italian
- Korean
- Spanish



## DISCLAIMER

The information contained in this newsletter is for informational purposes only, and should not be used to replace professional medical advice. Readers are responsible for how they chose to utilize this content. This information should not be considered complete, nor should it be relied on in diagnosing or treating a medical condition. It is best to seek advice and attention from your physician or qualified healthcare professional. Always consult your physician before beginning a new treatment, diet or fitness program.

## CONTACT INFORMATION

If you have further questions, including membership in our organization, please contact The Foundation via phone, post, or email, and we will assist you.

### Telephone:

Toll Free 1-866-VCFSEF5 (1-866-823-7335)  
From outside the US: 1-732-238-5494

### Postal address:

PO Box 874  
Milltown, New Jersey 08850  
USA

### Electronic mail:

General Information: [info@vcfsef.org](mailto:info@vcfsef.org)

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### Lay Council

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Philippe DE CLERCQ - 2010	<a href="mailto:pdeclercq@wordshop.fr">pdeclercq@wordshop.fr</a>
Ashli Chung - 2011	<a href="mailto:ashli@momerize.com">ashli@momerize.com</a>

### Ex-Officio

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