



VCFSEF NEWS

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Editor
Design & Layout

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FROM THE EDITOR

Editorial

Our current edition of the newsletter focuses on conferences! This last year certainly must distinguish the Foundation as being unique in having held TWO annual meetings in a single year! However, since the meetings were in different hemispheres on opposite sides of the globe (France and Australia), I think we should not only be forgiven but indeed applauded for bringing the newest research and clinical information to, and learning from, families worldwide.

In this issue Bronwyn Glaser reviews the two meetings for us and a selection of photographs from the meetings is included. We also wish to encourage as many of you as possible to register for the 2007 meeting in Dallas this July. Details and an outline of the program are included. Also included are our regular columns along with the periodic annotated bibliography of recently published articles. In the next edition we will feature another of our Global Forum features, this time on the challenges of finding appropriate medical care and advice. As I mentioned in my previous editorial, I am hoping to have a good deal of input from families in order to guide those discussions and so I would also like to receive suggestions for future Global Forum discussions that we might include. I would like to specially thank Kelvin Ringold for so expertly creating such an impressive final product from the jumble of pieces that I send to him. I look forward to meeting as many of you as possible in Dallas this coming July.

Tony J. Simon Ph.D.
Sacramento, CA

Inside this issue:

FAQs	2
Rays of Hope	3
From the Executive Director	3
From the President	4
Recent Donations	5
Strasbourg & Brisbane Report	6
Recent Publications	7
Regional Updates	10
Meeting Registration Form	12
14th Int'l Meeting Agenda	13
Annual Appeal Forms	17
VCFSEF Board Members	18

SAVE THE DATES!

**14th International
Scientific Meeting**

July 20–22, 2007

Marriott Dallas/Plano
at Legacy Town Center
Plano (Dallas), Texas
**ONLINE REGISTRATION
AVAILABLE**

See details at
www.vcfsef.org

**15th International
Scientific Meeting**

July 18-20, 2008
Troy (Detroit), Michigan

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Frequently Asked Questions

Edited by: Robert Shprintzen, Ph.D.

Question: I am following a young boy with VCF who has started having seizures. We are wondering if seizures are more common in people with VCF and if so is there any treatment that has been more successful?

Answer: Seizures in VCFS are relatively common and can be quite complex for a number of reasons. First, not all seizures in VCFS are the same. Some people with VCFS have seizures secondary to hypocalcemia. Hypocalcemic seizures can present as tremors in the arms and legs and loss of consciousness. The severity depends on the degree of hypocalcemia. Others have clonic seizures that can resemble hypocalcemic events. Absence seizures have also been observed. These usually involve staring and "blinking out" episodes. Clinical observations and EEG studies have also identified partial complex seizures in VCFS and some epileptiform seizures. Because it has been well documented that there are developmental anomalies of the brain and vascular anomalies related to blood supply to the brain, it would not be unusual to see seizures in children with VCFS and because there is variability in the types of brain anomalies, vascular malformations, and endocrine problems in VCFS, it would be unreasonable to expect that the diagnosis of VCFS would predict the specific types of seizures in an individual patient. *(Answered by Robert J. Shprintzen, Ph.D.)*

Question: My daughter is 11 years old and is being treated for hypothyroidism. Her endocrinologist has begun to discuss the possibility of hormonal treatments because of her short stature. I am wondering if any data or articles have been written on VCFS and short stature.

Answer: There is very little data available on long-term growth in children with VCFS. Several early publications (more than 20 years ago) hinted at "relative short stature" in VCFS, but these were cross-sectional studies, not longitudinal studies. Cross-sectional studies look at children at one moment in time and compare them to norms for the general population. Longitudinal studies follow children over time, preferably into adulthood, to see what their long-term outcomes are. In earlier reports, investigators did not have the advantage of following children for a long period of time because the syndrome was relatively new to most researchers. Now, some 30 years since the delineation of the syndrome, more data is available on adults. In papers delivered in Strasbourg and Brisbane at the two International Scientific Meetings of the VCFSEF this past year, the Syracuse research group reported that the frequency of abnormally short stature may not be any greater than in the general population, and that children with VCFS follow a different growth curve than children who do not have the deletion from 22q11. However, for the sample followed in the report (hundreds of cases), adult males with VCFS tended to reach what is referred

to as expected maximum height while females fell slightly short, but still within normal range. Expected maximum height refers to a rough estimate based on parental height and a somewhat arbitrary mathematical formula based on observations of many children over time. For boys, the calculation (in centimeters) is as follows:

$$\frac{(\text{father's height} + \text{mother's height}) + 5}{2} = \text{Expected Maximum Height}$$

For girls:

$$\frac{(\text{father's height} + \text{mother's height}) - 5}{2} = \text{Expected Maximum Height}$$

Approximately 2% of all children in the U.S. have abnormally short stature. Although it is not known if this rate is different for children with VCFS, at this point in time, the number of children with VCFS who have been treated with growth hormone is very small. Of course, stature in some children with VCFS will be affected by other anomalies associated with the syndrome including severe congenital heart disease, severe pulmonary problems, and even severe scoliosis. *(Answered by Robert J. Shprintzen, Ph.D.)*

VCFSEF Nominations

The Nominating Committee, chaired by Dr. Doron Gothelf, presented the following slate to the Board of Directors at its interim meeting. Voting by the membership will be at the Annual Membership Meeting in Plano, Texas on July 20, 2007.

President: Jennifer Lewandowski (USA)

Treasurer: Jeff Landsman (USA)

Secretary: Carrie Heran (USA)

Council Members:

(Professional, 3-year term): Merav Burg-Malki (Israel)

(Lay, 3-year term): Jennifer Stevens (USA)

(Lay, 1-year term): Philippe De Clercq (France)

Executive Director: pending

WORDS FROM THE EXECUTIVE DIRECTOR

Karen Golding-Kushner, Ph.D.

We are very busy planning our next International Scientific Meeting, which will be in Plano, Texas, near Dallas, July 20 -22, 2007. Keri Alexander and Dianne Altuna continue to make arrangements for the adult attendees and for the children participating in the Kids Zone, and the planning committee has put together a preliminary program that is included in this newsletter. We will be welcoming an international faculty of VCFS experts and look forward to hearing all the latest clinical and research information. Pre-registration is brisk and it is easier than ever to register because you can go online, click a few buttons, and be all done!

More information about the meeting and registration are in this issue and on our website. Once you have read about our two 2006 meetings in Strasbourg and Brisbane, you will want to be sure to register for the 2007 meeting in Texas. There is only one conference this year- don't miss out!

(Continued on page 4)

RAYS OF HOPE

In prior issues of the VCFS Educational Foundation newsletter, we have featured "Rays of Hope". This portion of our newsletter introduces us to those in our community who have overcome the challenges of VCFS and are willing to share their "Rays of Hope" with us all. If you would like to share a story or photo with us, please contact Maureen Anderson at mladja@aol.com

Madison

My daughter Madison was born four very long years ago. I say long, because she has been through more in her little life than my whole family put together. She was diagnosed Tetralogy of Fallot at birth and went into Congestive Heart Failure at 3 weeks old...for a long time, it was all downhill from there. To be brief, Madison has easily spent over 50% of her life admitted to the hospital, having more procedures, surgeries and illnesses than I could ever count. VCFS didn't take her life, but it took mine. For a long time, I did nothing but manage Madison's care. I was her secretary, her nurse, therapist, advocate...you name it.



I am telling you of this horrible tale, which almost brought all of us to our breaking point, because finally life is better and it was all worth it! Madison is 4 and ... and I can't believe it. Her admissions to the hospital are reduced to almost nothing now. She can't speak yet, but can sign her ABC's and count to 10. She knows all her colors, her same/opposites and is starting to write her letters. Madison runs on the playground, swims in the pool and eats like there is no tomorrow.

Our four-year journey has taught me patience and persistence, reminded me to keep the faith and strengthened every survival instinct I've ever had. I had no idea I had all of this in me. I had no idea Madison had the ability to endure so much with such grace and dig-

nity. I would never have learned so much about my child, my life and myself without her being diagnosed. What seemed like (for a long time!) the most horrible thing a mother could know, turned into a blessing I wouldn't wish on anyone, but have since learned to accept it as a gift.

Lisa

Noah

Noah was born with Tetralogy of Fallot, submucous cleft palate and one kidney. When he was three he was diagnosed with VCFS. He has had heart surgery and surgery for his speech and teeth.



When Noah was three he was diagnosed as developmentally delayed and put into a special pre-school. Now he is in first grade and in a special class for children with behavioral issues. He still has behavioral problems but Noah's academics are improving! He has problems with math and needs a lot of help but in reading he is actually above grade level!

I was told that Noah is the top speller in his class! I am so proud. He is showing me and others that just because he started out being delayed doesn't mean that he will always be. Noah is also a very helpful big brother to our nine-month-old. He is showing us that every child can achieve and they have strengths.

WORDS FROM THE EXECUTIVE DIRECTOR...

(Continued from page 3)

Mark your calendars! Next year's meeting will be July 18-20, 2008 in Troy, Michigan, just outside Detroit. Thank you to Jennifer Lewandowski and Fred Berg, who have already invested a lot of time in working with the Hilton Hotel to be sure all of our needs are met.

In other exciting news, Plural Publishing has released a new book by Donna Cutler-Landsman, past-president of the VCFSEF and the preeminent specialist in educating children and teens with VCFS. The book, entitled "A Practical Handbook for Education Children with Velo-cardio-facial Syndrome and Other Developmental Disabilities," is the first on this subject. This is a much-needed book that will undoubtedly become an indispensable resource for teachers and parents alike. Congratulations to Donna on this wonderful publication.

Finally, time has passed quickly and my four-year term as Executive Director ends at the close of our meeting in July. I have decided to decline an additional term and look forward to continuing to work with the Foundation as PAST-Executive Director while being more available to my family and speech therapy patients. As I reflect on the last four years, I see a Foundation that has strengthened its national and international connections and has met its mission to disseminate information with five scientific meetings in four years. As a result of scientists and clinicians networking at our scientific conferences, many important inter-institutional and even international collaborations have been formed and nurtured, leading to significant advances in our understanding of the heart, brain, behavior, and speech of people with VCFS.

I am proud that our newsletter has become an even greater source of clinical and research information and support than it was before. Our website offers more power point presentations and links to national and international groups, enabling anyone on the planet with an interest to access the latest information from world-renowned scientists and clinicians. We have worked toward increasing awareness of VCFS by adopting a slogan and logo, and putting them on wristbands, tee-shirts, and canvas bags. A long-awaited glossy brochure is also finally in print and will be available in time for the Dallas meeting. We've answered hundreds of phone inquiries called in to the toll-free number we established when I took office, and replied to thousands of emails. All of this was possible because of the many, many dedicated parents and professionals who generously gave of their time and resources to make it happen. I have enjoyed working closely with the Regional Directors, Board of Directors, committee chairs, and volunteers at every level. Most of all, it has been a true privilege to serve the members of this organization, the individuals with VCFS and their families, and the professionals who are so concerned about their well-being. I thank all of you for having given me that opportunity.

I look forward to seeing all of you in Plano.

Karen Golding-Kushner, Ph.D.
Executive Director

WORDS FROM THE PRESIDENT

"If I only knew then what I know now!" I have learned so much in the last year as VCFS President. I have been president officially for 9 months; planning since the 2005 conference in Syracuse. Most of my duties have been related to helping plan the 14th International Conference in my hometown of Dallas, Texas. Many of you reading this may be unaware that this is truly and International Foundation. In fact just last week, I had a conference call with Board members from Australia, Israel, Switzerland, and representatives in the U.S.A from New Jersey, New York, Wisconsin and California. As you might expect having an international presence allows us to work with some of the best doctors and medical professionals all over the world. Every one of these volunteers has a passion and love for VCFS. They donate their time and resources to learn and share their area of expertise with their peers and to the parents of children with VCFS.



I would be terribly remiss if I did not mention the unending gift we have with both Bob Shprintzen, Past Executive Director and Karen Golding-Kushner, our current Executive Director. Both give an ENORMOUS amount of time to the Foundation. Karen can easily spend 30 hours of donated time a week to our Foundation. We are no longer a small foundation. In the past few years, our place in the medical community has "boomed!" We are currently evaluating steps we need to take in order to keep up with the demands needed to run our foundation successfully. This requires staffing our foundation with exceptional professional and lay volunteers who will fulfill our dream of increasing awareness of Velo-Cardio-Facial Syndrome!

On a personal note, our local support group for North Texas is 2 ½ years old and we have 25 families on our

(Continued on page 5)

FROM THE PRESIDENT

roster. We meet four times a year to learn from speech pathologists, behavioral councilors, special education teachers, and local organizations that support children with learning differences, but mostly from parents of other children with VCFS who can often offer the best form of advise. We have laughed more than we have cried, but make no mistake about it, we are passionate about learning from anyone and anything we can to help our children. Starting a support group in your community will give you the tools needed for your journey with a child with VCFS. I have bonded with my support group members and they will be forever be a source of strength for Steve and me !

One way we have helped is to raise money for our Educational Foundation. My husband and I had 120 of our closest friends and family in our home for a night of food, fun and entertainment. We had the Maylee Thomas Band perform in our home. Since 1992 this band has donated their time to help raise more than \$1,000,000 for children's causes. It's fun when you find others who are passionate about children. Among these 60 couples we raised over \$22,000! We had several couples that wrote one check prior to the event, but felt moved to write a second check during the event. Moreover, another member of our support group is working on an additional fundraiser and hopes to raise \$5,000.00. These funds will be used to offset the cost of the meeting this July.

Please don't forget to order your light blue VCFSEF wristbands and our newly produced VCFSEF t-shirts. These shirts are available in both youth and adult sizes and are mailed from my home in Texas. The shirts and wristbands are available at www.vcfsef.org

Lastly we are working towards producing a 16-page brochure that can be handed out to doctors, parents, or anyone wanting to learn about VCFS. We plan to direct mail to 1000's of doctors in a variety of specialties who may have the opportunity to meet kids with VCFS. We hope that these doctors who come in contact with these children might have read the brochure and consider the possibility that this child might have VCFS. This will allow parents to feel some sort of relief as now they know what has been causing all the feeding, speech, delayed growth issues and some of the other 180 possible abnormalities that our precious children can suffer from. As our slogan says: Knowledge is Hope. We must get the word out to as many doctors as possible. We will have some brochures at the conference in Dallas, July 20-22. And if the brochures don't get you to Dallas, we hope the Dallas Cowboy Cheerleaders at our Friday night dinner will!

I plan to serve this organization in any way it needs me for the rest of my life! Steve and I feel so empowered by the education, advice and friendships we have received from this Foundation. Please join us and become a part of a family that our main goal is to give our children every opportunity to succeed in this precious life.

I hope to meet you in Dallas, July 20-22!!

Keri Alexander

DONATIONS

The VCFS Educational Foundation relies on membership dues and donations to fulfill its mission to disseminate information regarding the syndrome. We gratefully acknowledge the following individuals and organizations for their donations that were made since our last newsletter.

General Gifts:

In honor of Polly & Bill Parson:

Patti Parson

In honor of Christy Parson:

Melissa Parson

In Honor of Allison Robbins:

Mr & Mrs Robert Cohen

In Honor of Rhet Alexander

Junette Buenconsejo

Larry & Judy King

In Honor of Mary Christine Viere

Ruth Slaughter

Jane Marion Viere

In Honor of Jack Ullian - Happy Birthday

Gayle Fleischer & Scott Obler

In Memory of Milton Shprintzen:

VCFSEF Board & Regional Directors

Ahmad Al-Khattat

Jeffrey Landsman

Karen Golding-Kushner and Stuart Kushner & Family

Nathaniel Robin

Steve & Keri Alexander

Bronwyn Glaser

Tony Simon

In memory of Timothy A Holland

Alice Daisley

Robert & Charlene Parks

Brian & Julie Cooper

In memory of Michael Wolff:

Mr & Mrs. Robert Cohen

Corporate Gifts:

The Corporate Research Group

United Way Campaign:

Valerie Diagnazio

Kid's Zone

Jennifer Graham

Jaime Scheid

Dean Gadd

Junette Buenconsejo

Ruth Slaughter

Jane Marion Viere

To date we have received donations in the amount of **\$7,670** since the last newsletter.

Thank you to all of our generous donors and to those who solicited their support.

Report of Strasbourg & Brisbane International Scientific Meetings

By Bronwyn Glaser, Geneva Switzerland

The overwhelming success of the two international conferences this year was representative of the continued growth of the VCFS-EF and knowledge about VCFS in general. These three-day events during which

researchers, practitioners and families meet are not only great fun, but they also help us to move forward with our common goals of understanding the main difficulties associated with VCFS and supporting affected individuals. For those of you who could not be there to share in the meetings in Strasbourg, France in July 2006 and in Brisbane, Australia in November 2006, here's a brief taste of some of the main topics that were discussed and presented.

Discussions of the social difficulties associated with the syndrome were of specific interest to attending families. Several research groups are now using different approaches to study psychosocial development during childhood and adolescence. One approach is to understand how cognitive difficulties may relate to and influence social functioning, and which impairments may pose the biggest challenge to developing the social relationships that are key to well-being. For example, data were presented at both conferences showing that individuals with VCFS tend to focus on peripheral details when observing a social interaction, rather than key elements, such as gaze direction, expression, and body language. This may be one reason that we observe problems in reading and interpreting social nuances in the syndrome. Another approach being used to study psychosocial difficulties is to document the occurrence and frequency of different social and psychiatric problems in VCFS, such as communication problems, attention difficulties, social withdrawal, anxiety, and risk factors for psychosis. This is especially important for understanding the relationship between behaviors and problems that may signal the need for psychiatric treatment. And finally, evidence was presented for ways to remediate and support social development using behavioral support strategies, mentoring programs, and cognitive remediation. Intervention suggestions will likely take an even bigger place in years to come. Indeed, the better we understand the relationships between the problems that occur in VCFS, the more it will be possible to



Strasbourg attendees focus on presentation.

support and treat an individual as he/she develops.

However, the challenge of both defining the social difficulties associated with VCFS and applying appropriate treatment strategies also means understanding why certain behaviors occur. This idea was discussed at the Strasbourg conference in the context of a recent report of frequent autistic-like problems in children with VCFS. Similar to children with autism, children with VCFS often exhibit social inhibition and avoidance, communication problems, and some perseveration; however, the average level of functioning, as well as the motivation and pleasure that individuals with VCFS receive from social contact and relationships, distinguishes the two conditions. The debate at the conference centered on the underlying pathology of "autistic-like" traits in VCFS, and why the two conditions may look similar. If social inhibition and withdrawal are more associated with other psychological challenges in VCFS, they should be monitored and treated in the appropriate context.



Martin Debbané of Switzerland addresses the Strasbourg attendees.

Whether or not to medicate a VCFS child for attention problems is a concern facing many families, and one that should also be approached "syndrome-specifically". Discussions in Strasbourg revealed that

(Continued on page 11)

Annotated Bibliography of Recent Publications

Wendy R. Kates, Ph.D. and Nuria Abdul Sabur, B.A.

Brain Structure and Function

Several structural and functional brain-imaging studies were published during the past year. Structural brain imaging studies focus on the size or volumes of brain regions that investigators believe affect cognition or behavior in VCFS. Functional brain imaging studies focus on the extent to which regions of the brain are activated while the subject lies in the MRI scanner performing a specific cognitive task.

1.) Debbane M, Schaer M, Farhoumand R, Glaser B, Eliez S. (2006) Hippocampal volume reduction in 22q11.2 deletion syndrome. *Neuropsychologia*. Volume 44: pp. 2360-5.

This study used structural brain imaging to investigate the size, or volume, of the hippocampus, a brain region that we know is critical to learning and memory. The study was conducted on 43 children and adults with VCFS, and 40 healthy individuals who were matched for age and gender. The investigators found that the volumes of the hippocampus in individuals with VCFS were significantly smaller than those of healthy controls. Hippocampal reductions were disproportionate to overall gray matter reductions that have been reported previously in the brains of individuals with VCFS. The authors suggest that hippocampal reductions may be related to documented memory deficits and risk for schizophrenia in VCFS, but they note that additional studies are needed to confirm these associations.

2.) Kates WR, Miller AM, AbdulSabur N, Antshel KM, Conchelos J, Fremont W, Roizen N. Temporal lobe anatomy and psychiatric symptoms in velocardiofacial syndrome (22q11.2 deletion syndrome). *Journal of the American Academy of Child and Adolescent Psychiatry*. Volume 45: pp. 587-96.

This study used structural brain imaging to investigate the volumes of the prefrontal cortex and amygdala, and the association between those volumes and psychiatric symptoms in children and adolescents with VCFS. The prefrontal cortex and the amygdala are both critical to emotional processing. Brain volumes and scores on behavioral measures were compared among 47 children with VCFS, 15 of their siblings, and 18 community controls. The investigators found that relative to healthy controls and siblings, youth with VCFS exhibited 11% larger volumes of the left amygdala and 8% larger volumes of the right amygdala. Children with VCFS also exhibited smaller ratios of prefrontal to amygdala volumes. For children with VCFS, but not for the comparison samples, larger volumes of the amygdala and smaller ratios of prefrontal cortex to amygdala were associated with higher scores on the anxiety and aggression scales of the Child Behavior Checklist. These findings suggest disturbances in the prefrontal – amygdala neural network may underlie, in part, the impairments in managing emotions that have been described in youth with VCFS.

3.) Bearden CE, van Erp TG, Dutton RA, Tran H, Zimmermann L, Sun D, Geaga JA, Simon TJ, Glahn DC, Cannon TD, Emanuel BS, Toga AW, Thompson PM. (2006) Mapping Cortical Thickness in Children with 22q11.2 Deletions. *Cerebral Cortex* (published on-line).

This is a structural imaging study that used advanced computational analyses to compare the thickness of the cerebral cortex between 21 youth with VCFS and 13 matched, healthy controls. The investigators found evidence 6% to 10% reductions in cortical thickness in the parietal and occipital cortices, which are critical to visual – spatial perception and processing. These findings are consistent with previous studies that have reported volume reductions in the parietal lobes of youth with VCFS. Up to 14% reductions in cortical thickness was also observed in specific regions of the frontal lobe that are associated with language development, which is known to be delayed in VCFS.

4) Campbell LE, Daly E, Toal F, Stevens A, Azuma R, Catani M, Ng V, van Amelsvoort

T, Chitnis X, Cutter W, Murphy DG, Murphy KC. (2006) Brain and behaviour in children with 22q11.2 deletion syndrome: a volumetric and voxel-based morphometry MRI study. *Brain*. Volume 129: pp. 1218-28.

This structural imaging study used multiple methods of measurement and analysis to investigate the association between brain volumes and psychiatric symptoms in VCFS. The sample consisted of 39 youth with VCFS and 26 unaffected, sibling controls. The study investigated both gray matter, where informational processing takes place, and white matter, where information is transferred from one brain region to another. Consistent with previous stud-

Annotated Bibliography of Recent Publications ...

ies, youth with VCFS exhibited reductions in the white matter of the frontal lobe and the gray and white matter of the cerebellum (a region at the base of the brain that is involved in both movement and cognition). VCFS youth also exhibited reductions in the parietal and occipital lobes, and increases in the caudate nucleus (a brain region involved in movement). These brain alterations were associated with several psychiatric symptoms, suggesting that frontal-cerebellar and frontal-caudate networks may underlie psychiatric vulnerability in youth with VCFS.

5.) Kates WR, Antshel KM, Abdulsabur N, Colgan D, Funke B, Fremont W, Higgins AM, Kucherlapati R, Shprintzen RJ. (2006) A gender-moderated effect of a functional COMT polymorphism on prefrontal brain morphology and function in velo-cardio-facial syndrome (22q11.2 deletion syndrome). *American Journal of Medical Genetics, Neuropsychiatric Genetics*. Volume 141: pp. 274-80.

Investigators are becoming increasingly interested in determining how genetic variation in the non-deleted section of chromosome 22q11.2 affects brain structure and function. The COMT gene, which is deleted on one copy of chromosome 22q11.2, is very interesting because it encodes a protein that is involved in information processing in the frontal lobe of the brain. The COMT gene has two variants, known as the Met variant and the Val variant, each of which appears to affect cognition differently. Individuals with VCFS have one copy of either the Met variant or the Val variant. This study investigated the effect of these COMT variants on volumes of the orbito-frontal cortex, which is involved in behavioral inhibition. The investigators found an association between the COMT variant and the volumes of the orbito-frontal cortex; however this association depended on whether the participant was male or female. Girls with the Met variant and boys with the Val variant both had smaller volumes of the orbito-frontal cortex than girls with the Val variant and boys with the Met variant. These findings suggest that the COMT gene may play a gender-dependent role in determining the frontal neuroanatomy in VCFS.

6.) Gothelf D, Hoefl F, Hinard C, Hallmayer JF, Van Dover Stoecker J, Antonarakis

SE, Morris MA, Reiss AL. (2007) Abnormal cortical activation during response inhibition in 22q11.2 deletion syndrome. *Human Brain Mapping* (published on-line).

This is a functional imaging study that tested the participants' ability to inhibit responses. Participants included 13 adolescents with VCFS, 14 typical controls, and 9 controls with developmental disabilities. During the task, the group of adolescents with VCFS exhibited increased levels of parietal lobe activation relative to the other samples. The authors suggest that youth with VCFS utilize the parietal lobe to compensate for deficits in inhibiting responses. The study further investigated the effect of the COMT Met and Val variants on brain activation in subjects with VCFS. Compared to youth with the Val variant, those with the Met variant displayed increased activation of the cingulate, a brain structure involved in attention and inhibition. These findings suggest that the COMT gene also significantly influences brain function in VCFS.

7.) van Amelsvoort T, Schmitz N, Daly E, Deeley O, Critchley H, Henry J, Robertson

D, Owen M, Murphy KC, Murphy DG. (2006) Processing facial emotions in adults with velo-cardio-facial syndrome: functional magnetic resonance imaging. *British Journal of Psychiatry*. Volume 189: pp. 560-1.

In this functional imaging study, eight adults with VCFS and nine healthy controls viewed faces exhibiting either anger or happiness. Relative to control participants, individuals with VCFS exhibited less brain activation in several brain regions involved in emotion processing, including the frontal lobe and the insula. VCFS participants also exhibited more brain activation than controls in the occipital region. These findings, although preliminary due to the small sample size, suggest that disturbances in brain networks involved in emotion processing may underlie social deficits in individuals with VCFS.

Behavioral and Psychiatric Functioning

1) Gothelf, D., Feinstein, C., Thompson T., Gu, E., Penniman, L., Van Stone, E., Kwon, H., Eliez, S., Reiss, A.L. (2007) Risk factors for the emergence of psychotic disorders in adolescents with 22q11.2 deletion syndrome. *American Journal of Psychiatry*, Vol. 164: 663-669.

This study investigated early risk factors for the development of psychotic disorders by assessing a sample of 29 individuals with VCFS and 31 age- and IQ-matched controls twice during a five-year time span. At the second, follow-up assessment (Time 2), they found that 32.1% of individuals with VCFS had developed psychotic disorders as

(Continued on page 9)

Annotated Bibliography of Recent Publications...

(Continued from page 8)

compared with 4.3% of the comparison subjects. The presence of anxiety and mild psychotic symptoms at the Time 1 assessment, and a reduction in verbal IQ scores between Time 1 and Time 2 were the strongest predictors of psychosis at Time 2. The presence of the Met variant of the COMT gene also appeared to predict the presence of severe psychiatric symptoms at Time 2.

2) Antshel, K.M., Aneja, A., Strunge, L., Peebles, J., Fremont, W.P., Stallone, K., AbdulSabur, N., Higgins, A.M., Shprintzen, R.J., Kates, W.R. (2006) Autism spectrum disorders in velo-cardio Facial Syndrome (22q11.2 deletion). *Journal of Autism and Developmental Disorders*, online: December 12, 2006.

This study investigated the difference between children with VCFS and autism spectrum disorder (ASD) and those with VCFS alone. The sample consisted of 41 children with VCFS. Eight children with VCFS met formal criteria for autism. An additional nine participants exhibited autism symptoms but did not have "full-blown" autism. Of the 17 children with either autism or autistic symptoms, 94% had a co-occurring psychiatric disorder, compared to 60% of children with VCFS – only who had a psychiatric disorder. This study has implications for early identification and treatment of children with VCFS and autism-spectrum symptoms.

3.) Vorstman, J.A., Morcus, M.E., Duijff, S.N., Klaassen, P.W., Heineman-de Boer, J.A., Beemer, F.A., Swaab, H., Kahn, R.S., van Engeland, H. (2006) The 22q11.2 deletion in children: high rate of autistic disorders and early onset of psychotic symptoms. *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 45: 1104-1113.

This study also investigated the rate of autism in VCFS and the association with psychiatric disturbance. Up to 50% of participants with VCFS had autistic-spectrum symptoms, and a sizeable proportion of those children also had co-occurring symptoms of psychosis. Interestingly, IQ did not have an effect on these rates of psychopathology. Like the study described above, these findings carry important implications for early identification and treatment of VCFS-affected children with behavioral and social deficits.

4) Lewandowski, K.E., Shashi, V., Berry, P.M., Kwapil, T.R. (2007) Schizophrenic-like neurocognitive deficits in children and adolescents with 22q11 deletion syndrome. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, Vol. 144: 27-36.

This study investigated cognitive deficits in 26 children with VCFS and 25 controls. As compared to peers, children with VCFS scored lower on tests of intelligence, achievement, executive functioning, sustained attention, and verbal working memory. Deficits in attention and executive function (ie., the ability to initiate, plan and organize) were disproportionate to reductions in IQ. In other words, these deficits were not accounted for by overall deficits in cognitive function. These findings are consistent with previous studies, and the authors note that that this pattern of cognitive deficits present in children with VCFS is comparable to that seen in schizophrenic patients.

Book Chapters

Simon, T.J., Burg-Malki, M., & Gothelf, D. (2007) Cognitive and behavioral characteristics of children with chromosome 22q11.2 deletion. In M.M.M. Mazzocco & J.L. Ross (Eds.) *Neurogenetic Developmental Disorders: Manifestation and Identification in Childhood*. Cambridge, MA: The MIT Press.

This chapter reviews the physical, psychiatric, cognitive and academic manifestations of VCFS. It provides an in-depth and comprehensive focus on the cognitive strengths and deficits of youth with VCFS from the perspectives of neuropsychological assessment and cognitive experimental studies.

(This chapter can be downloaded in PDF form under the "Publications by CABIL Team" link at: <http://cabil.mindinstitute.org>)

Kates, W.R. & Fremont, W. Velo-cardio-facial syndrome. In *The Spectrum of Psychotic Disorders*. D. Fujii & I. Ahmed, Eds. Cambridge University Press: Cambridge: 2007.

This chapter focuses specifically on the psychiatric phenotype in VCFS. The authors review the behavioral, neurobiological and potential genetic contributions to severe psychiatric disorder in VCFS.

REGIONAL UPDATES

Regional Update from Latin America — The VCFS patients and families from Latin America send greetings to everyone in the Foundation. The group from Argentina (one of the few in all Latin America) is planning to attend the meeting in Dallas. This will be the first participation from a Latin American group in Foundation's Scientific meeting. They are also planning to organize a meeting in Argentina next year. They sincerely hope Bob Shprintzen will be able to accept a very special invitation to this meeting.

At this point in time, the Spanish version of the last newsletter should be available on the Foundation's site. The forum on ADHD was particularly interesting since there was a communication from a Spanish family. The newsletter will keep being translated into Spanish and this version will be available on the Foundation's site. Saludos a todos.....Antonio Ysunza. Mexico City

Regional Update from Europe — Greetings from across the pond! The European branch of the VCFS-EF has had a busy year, with new family associations being formed and plans are underway to propose that the 2009 VCFS-EF annual meeting be held in beautiful Rome!

One of the original objectives of the European branch was to create a European network that would align professionals and make resources increasingly available in Europe. Creating family associations in as-yet unconnected regions is one great way to reach out to more families, so we are very pleased to announce recent family associations in Ireland, and Relais22 in French-speaking Belgium! One of the first events of Relais22 was a conference in Brussels, at which professionals from Europe came to speak to the more than 30 member families. President Isabelle Vanlathem (communication@relais22.be) and other members are working hard to make information readily available via the group's internet site and regular scientific meetings. It is wonderful to have an association in French Belgium, given the large surrounding groups in France and Flemish-speaking Belgium! Welcome on-board to both Relais22 and the Irish association!

The conference in Strasbourg was a great success last July and reached out to many European families for the first time. We hope that the 2009 conference in Rome will tempt families in Europe, as well as families outside of Europe who long for a fantastic vacation! We will keep you posted as the conference details take shape, but we wanted to spread the word already. It is a wonderful way to spend a vacation eating, seeing historical sites, and of course, learning about VCFS!.....Bronwyn Glaser, Geneva

Preliminary Program for 2007 International Scientific Meeting

The Program for the 14th Annual International Scientific Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. is shaping up to be another major event.

Friday will be a day focusing on speech disorders and their treatment, feeding issues, growth and development, and function of the muscles of the throat and palate. On Saturday, the morning will be spent discussing clinical and molecular genetics, brain structure and function, how the genome relates to behavior and mental illness. The afternoon will focus on psychiatric disorders, including treatment and medications. On Sunday, there will be more discussion of medical issues related to psychiatric illness with a guest speaker, Dr. Stuart Kushner, who will discuss how drugs for psychiatric disorders are developed by drug companies and approved for use by the FDA.

A panel session on the diagnosis of autism in VCFS is also planned and is bound to be a highlight of the meeting. Sleep disturbance in VCFS will also be reviewed.

Last, and certainly not least, a session on education and how to effectively intervene to maximize educational outcomes will be held on Sunday morning. The faculty will include speakers from all over the U.S., Europe, Israel, South America, and Mexico. They will include many well-published researchers and past participants in our meetings, such as (in alphabetical order): Ahmad Al-Khattat (Great Britain), Robert Beecher (Milwaukee, WI), Bronwyn Glaser (Switzerland), Doron Gothelf (Israel), Anne Marie Higgins (Syracuse, NY), Wendy Kates (Syracuse, NY), Karen Golding-Kushner (East Brunswick, NJ), Donana Landsman (Madison, Wisconsin), Susan Marks (Milwaukee, WI), Frank Middleton (Syracuse, NY), Bernice Morrow (Bronx, NY), Robert Shprintzen (Syracuse, NY), Tony Simon (Sacramento, CA), Antonio Ysunza (Mexico City).

In addition to these visitors to the Dallas-Fort Worth area, there will also be a number of distinguished local faculty members headed by Dianne Altuna who has been an active participant in program planning. Keri Alexander and her local arrangements committee have done a superb job in planning the social activities for the meeting and this 14th annual event will not disappoint the registrants.

In this early stage of planning, days and times may shift, and we would like to remind our readers that abstracts and program suggestions are still being accepted.

Report of Strasbourg & Brisbane International Scientific Meetings

(Continued from page 6)

treatment of attention problems varies greatly by geographic region. In France, many child psychiatrists are against Ritalin-type treatments, whereas medication for children with inattention problems is more frequently prescribed in Anglo-Saxon countries. However, independent of differing views on medication, the Ritalin debate underscores the need for psychiatrists to be familiar with the range of difficulties associated with VCFS. Indeed, if an individual is at-risk for psychotic symptoms, such as hallucinations or delusions, then medications for attention problems can increase their incidence. Psychopharmacological treatment, individualized school programs, and remediation should be approached comprehensively, with all aspects of the syndrome in mind.

Finally, as for previous conferences, much time and thought was dedicated to academic and learning problems in VCFS. This year, however, Donna Cutler-Landsman, a teacher and parent of an individual with VCFS, has enriched the discussions by writing a book



Donna Landsman answers some audience questions after her presentation in Brisbane.

about learning problems in the syndrome and specific ways of approaching them. *Educating Children With Velo-cardio-facial Syndrome* is a product of Donna's ideas and research, as well as requests from families for specific ideas and strategies to help navigate through academic challenges. Donna's book is yet another indication of increased resources for families and practitioners, and hopefully represents the first of many bridges between research findings and concrete ideas for supporting children through the school years. If you are interested in ordering Donna's book, it is available at

the Plural Publishing website :
(www.pluralpublishing.com, ISBN: 1-59756-109-60).

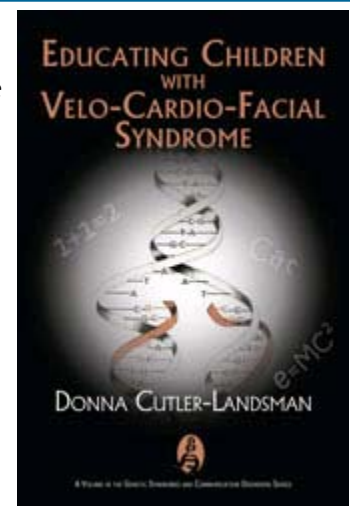
The above discussion represents only a tiny portion of the material presented at the conferences in Strasbourg and Brisbane in 2006. Each year, the conferences grow richer in ideas and information, thanks to increasing professional interest and families' willingness to share their experiences and personal challenges. French and Australian families were particularly appreciative of the chance to benefit locally from these events this year; and the VCFS-EF will continue to organize conferences in new locations to reach those who have not yet had an opportunity to attend. The next international conference will be held in Dallas, Texas from July 20-22, 2007. Information can be found on the [VCFSEF website](http://www.vcfsef.org).



Ahmad Al Khattat addresses a full house in Brisbane, Australia.

Virtually 100% of children with Velo-cardio-facial-syndrome need special educational programming.

This is the only book available that addresses the educational needs of this population, effectively blending the thoughtful research that has transpired within the past 10 years with practical and current educational strategies to better meet the needs of children with VCFS and other developmental disabilities.



July 20 - 22, 2007, Plano, Texas

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

(This program is tentative and changes may be made prior to July 20 without prior notice. Please check the Foundation web site, www.vcfsef.org for program updates as available.)

Friday Morning, July 20, 2007

8:00 – 9:30 A.M.: Registration

8:30 – 9:30: Primer Session: These sessions are optional and are designed to familiarize registrants with the basics of the major subject areas discussed during the meeting. Experts will discuss common terms used during the presentations and discuss the fields of study in general terms. Registrants interested in these sessions must pre-register for one session only.

1. Speech, Feeding, and Hearing Disorders: Dianne Altuna, Dallas, TX; Robert Beecher, Milwaukee, WI; Susan Marks, Milwaukee, WI; Antonio Ysunza, Mexico City
2. Medical and Clinical Genetics: Bernice Morrow and Alan Shanske
3. Psychiatry and Brain Imaging: Wendy Kates, Doron Gothelf, Bronwyn Glaser

9:30 – 10:00: Opening Ceremonies and Introduction

Keri Alexander, President, VCFSEF

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

10:00 – 10:05: The Educational Foundation: Past Accomplishments, Future Challenges; *Robert J., Shprintzen, Ph.D., Past-Executive Director, Founder VCFSEF*

10:05 – 10:25: The International Scene: Latin America, Middle East, Europe, and Australia.

10:25 – 10:45: Variable expression of VCFS: what explains differences in severity?; Alan Shanske, M.D., Bronx, NY

10:45 – 10:55: Questions and discussion

10:55 – 11:10: Refreshment Break

11:10 – 11:30: Feeding, growth, and weight gain in VCFS; Robert Beecher, Milwaukee, WI

11:30 – 11:45: Are Children with VCFS Apraxic? *Karen J. Golding-Kushner, Ph.D., East Brunswick, NJ;*

11:45 – 12:00: Cognition in 3_ year olds with VCFS; *Sasja Duijff, M.Sc.; Petra Klaassen, M.Sc.; Henriette de Veye, M.Sc., Ph.D.; Monique Sijmens, M.Sc.; Jacob Vorstman, M.D.; Gerben Sinnema, M.Sc., Ph.D.; Frits Beemer, M.D., Ph.D., Utrecht, The Netherlands*

12:00 – 12:15: Questions and Discussion

12:15 – 1:30: Lunch with the Experts

1. Leg Pains: Ahmad Al-Khattat
2. Genetics: Alan Shanske, M.D.; Bernice Morrow, Ph.D., Angela Scheuerle, M.D.
3. Feeding: Robert Beecher, M.S.

Friday afternoon

- 1:30 – 1:50: An Anatomical and Physiological Explanation of Velopharyngeal Function; *Antonio Ysunza, M.D., Mexico City*
- 1:50 – 2:10: Surgical Planning for Hypernasal Speech: 35 Years Studying Outcomes; *Robert J. Shprintzen, Ph.D., Syracuse, NY*
- 2:10 – 2:20: Questions and Discussion
- 2:20 – 2:50: **Special Panel Session**
Come Blow Your Horn: Why DO They Call It **SPEECH** Therapy?; *Dianne Altuna, M.S., Dallas, X;*
Karen J. Golding-Kushner, Ph.D., East Brunswick, NJ;
Susan Marks, M.S., Milwaukee, WI, Moderator
- 2:50 – 3:05: Refreshment Break
- 3:05 – 3:20: A phonological approach to speech therapy in VCFS; *Virginia Dixon-Wood, M.A., Gainesville, FL.*
- 3:20 – 3:35: Eliminating abnormal compensatory articulation patterns in VCFS: treatment and outcomes;
presenter to be announced
- 3:35 – 3:50: What do you do when you can't find a speech therapist? *Sandra Ochoa, Weslaco, TX*
- 3:50 – 4:05: Teletherapy: using technology to solve the problem; *Karen J. Golding-Kushner, Ph.D., East Brunswick, NJ*
- 4:05 – 4:20: Intensive Speech Therapy in a Summer Camp Setting; *Dianne Altuna, M.S., Dallas, TX*
- 4:20 – 4:35: Questions and Discussion
- 4:35 – 4:55: Leg Pains in VCFS; *Ahmad Al-Khattat, Northampton, UK*
- 4:55 – 5:00: Questions and Discussion
- 5:00 – 6:00: Annual Business Meeting: All members should attend

Saturday Morning, July 21, 2007

- 8:00 – 9:00: Breakfast with the Experts
1. Early speech development: Dianne Altuna, Karen Golding-Kushner, Susan Marks
 2. Education: Donna Landsman
 3. To be announced
- 9:00 – 9:30: Genetic Modifiers and Genetic Susceptibility in VCFS; *Bernice Morrow, Ph.D, Bronx, NY*
- 9:30 – 9:50: Microarray-based analyses of VCFS; *Frank Middleton, Ph.D., Syracuse, NY*
- 9:50 – 10:20: Investigating a potential modifier of VCFS in mice; *Anne Moon, M.D., Ph.D., Salt Lake City, Utah*
- 10:20 – 10:35: Questions and Discussion
- 10:35 – 10:50: Refreshment break
- 10:50 – 11:10: Progress toward building a better model of the human disease: Tbx1 dosage modulation in mice; *Antonio Baldini, M.D., Houston, TX*
- 11:10 – 11:30: Can we model behavioral/psychiatric disorder in laboratory animals? *Elizabeth Illingworth, Ph.D., Houston, TX*
- 11:30 – 12:00: Neural Imaging, Behavior, and Genomic Analysis: From Genes to Brain to Behavior; *Wendy Kates, Ph.D., Syracuse, NY*
- 12:00 – 12:15: Questions and Discussion
- 12:15 – 1:30: Lunch with the Experts
1. The Importance of Financial and Legal Planning for Special Needs Families: Candace Hurt, CFM, CFP, CSNA; Pam Whitney, CSNA,; Lisa L. Wilson, PLLC
 2. Routine health care in VCFS: Alan Shanske, Robert Shprintzen; Dr. Joseph Peterman
 3. Orthodontics: James Mulick, D.D.S.

TEEN AND YOUNG ADULT LUNCH: TALKING ABOUT VCFS*Alexandra Oppenheimer, M.Ed., Larchmont, NY****Saturday afternoon***

- 1:30 – 2:15: Problems with space, time and numbers: A new mind and brain explanation; *Tony Simon, Ph.D., Sacramento, CA*
- 2:15 – 3:00: Face processing and social impairments in VCFS, *Bronwyn Glaser, M.A., Geneva, Switzerland*
- 3:00 – 3:15: Questions and Discussion
- 3:15 – 3:30: Refreshment Break
- 3:30 – 3:50: Longitudinal perspective on genes, brain and behavior in VCFS. *Doron Gothelf, Petah Tiqva, Israel.*

- 3:50 – 4:15: Autism in neurogenetic syndromes. *Doron Gothelf, Petah Tiqva, Israel.*
- 4:15 – 4:35: Functional Imaging of Cognition and Emotion in VCFS; *Wendy Kates, Ph.D., Syracuse, NY*
- 4:35 – 4:50: Behavioral problems in young children with VCFS. *Petra Klaassen, M.Sc.; Sasja Duijff, M.Sc.; Henriette de Veye, M.Sc., Ph.D.; Monique Sijmens, M.Sc.; Jacob Vorstman, M.D.; Gerben Sinnema, M.Sc., Ph.D.; Frits Beemer, M.D., Ph.D., Utrecht, The Netherlands*
- 4:50 – 5:00: Questions and discussion

Sunday Morning, 9 July 2007

- 8:00 – 9:00: Breakfast with the Experts:
1. Speech therapy in the older child: *Dianne Altuna, M.S.; Karen J. Golding-Kushner, Ph.D.; Susan Marks, M.S., Tony Ysunza, M.D.*
 2. Psychiatry/Behavior: *Bronwyn Glazer, Doron Gothelf, Wendy Kates, Tony Simon*
 3. Leg Pains: *Ahmad Al-Khattat*
- 9:00 – 9:45: Educational Interventions for Children with VCFS; *Donna Cutler-Landsman, M.A., Madison, WI, USA*
- 9:45 – 10:00: Questions and Discussion
- 10:00 – 10:20: Developing a drug for psychiatric disorders in children: From Planning to FDA approval; *Stuart Kushner, M.D., East Brunswick, NJ*
- 10:20 – 10:30: Questions and Discussion
- 10:30 – 10:45: Refreshment Break
- 10:45 – 11:15: Panel: The Autism Controversy; *Doron Gothelf, M.D., Petah Tiqva, Israel; Wendy Kates, Ph.D., Syracuse, NY; Frank Middleton, Ph.D.; Tony Simon, Ph.D.*
- 11:15 – 11:25: The smile that changed our world; *Jennifer Stevens, Point Pleasant, NJ*
- 11:25 – 11:40: Orthodontic management in VCFS; *James Mulick, D.D.S., Agoura Hills, CA*
- 11:40 – 11:55: Sleep Disturbance in children with VCFS, *Robert J. Shprintzen, Ph.D., Syracuse, NY*
- 11:55 – 12:00: Questions and Discussion
- 12:00: Conclusion: Closing comments

Poster Session:

Clinical Aspects of VCFS in a Pediatric Hospital in Argentina
E. de Castro Perez; M. Olastro; A. Ornani; G. Zelaya; S. Reyes; M. Ortega; M.G. Obregon; Pichincha, Argentina

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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 on the inside.

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You can purchase your bracelets directly from the foundation's web site at <http://vcfsef.org/Donations/wrist.html>. Online payments are processed through PayPal.

For questions regarding wrist bands, contact Nancy Robbins at nirrobbins@aol.com.



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://vcfsef.org/t_shirts.html. 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. Online payments are processed through PayPal.

For questions regarding tee shirts, including shipping cost to other destinations, contact Keri Alexander directly at skalex1@tx.rr.com.



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