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Volume 16, Issue 2

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Salt Lake City, Utah, host 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.

Newsletter Deadline

All contributions for the next VCFSEF newsletter should be sent to editor@vcfsef.org by May 15th, 2010. Given the time of year, the theme will be recreation and social opportunities/challenges for individuals with the VCFS.



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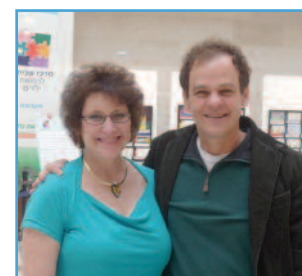
GREETINGS FROM THE EDITOR



Sue Carneol, MS,
CCC-SLP

Greetings! It is hard to believe that we are into our second edition of the VCFSEF newsletter for 2010. While I have never actually seen “time fly”, it sure feels like it does. I look at my children who have grown into young adults and wonder “when did that happened?” I marvel at the passage of time when I see long-time patients return for re-evaluations. Their visits allow me to celebrate, collaborate, and commiserate with parents on their child’s accomplishments, challenges and future plans. This edition of the newsletter will be devoted “Transitioning to Adulthood” for adolescents with Velocardiofacial Syndrome. In our new column, Research Round-Up, you will read about a research study that was recently completed looking specifically at the needs of this age group. The question posed in our FAQ points to the increased

learning and social-emotional demands these young people face. You will also meet an adult who was recently diagnosed with the syndrome and can read her reactions to that discovery. A previous column, The Global Forum, has been resurrected for this issue. The articles include stories of families and young adults from across the world and responses from experts, who specialize in working with this age group.



Sue meets
Doron Gothelf
at Schneider
Medical Center
in Israel
January 2010

Finally, the planning committee for the 17th Annual Scientific meeting of the VCFSEF in Salt Lake City has been very busy putting together a fantastic program.

The Program and Activities for the 17th Annual International Scientific Meeting of the VCFSEF, Inc. are Being Planned and Your Input is Invited

The Program Committee for the 17th Annual International Scientific Meeting of the VCFSEF, Inc. to be held in Salt Lake City, Utah, July 16 to 18, 2010, has been meeting via conference calls every other week for months now to assure another successful meeting. The meeting will be held at the Sheraton Salt Lake City, a superb venue for this meeting. The actual scientific portion of the meeting begins Friday morning, July 16, but this year, we are planning a welcome get together around the swimming pool on Thursday night for those who will arrive the day before the meeting begins. The optional dinner this year will be held Friday evening and some interesting and enjoyable entertainment is being planned. Can't say too much about it yet except to say that you will be very pleasantly surprised. What we CAN say is that evening will include our first-ever Talent Showcase, and everyone is invited to participate (See Executive Director's report).

The scientific meeting will cover all aspects of VCFS presented by the world's leading authorities. As always, there will be individual private consultations with experts in a variety of areas, such as speech, feeding, and growth and development. A major topic will be the transition to adult life for people with VCFS. There will also be information on transitioning children from tube feedings to oral feeding. Please go to the Educational Foundation's web site to see the preliminary program and to obtain an abstract form for submission of presentations, registration, and a link to make your hotel reservations at a rock-bottom price of \$99 per night.

[Conference Registration Link](#)

[Submit a Paper Link](#)

[Talent Show Entry Form Link](#)

[Hotel Reservation Link](#)

Greetings from the Editor *(Continued from page 1)*

Steve Orton, our president, urges us to make a family vacation around the conference and enjoy the natural beauty and fun things to do in the area.

Our next newsletter will be in June. Given the time of year, the theme will be recreation and social opportunities/challenges for individuals with the syndrome. The deadline to submit articles will be May 15. Submissions can be sent to editor@vcfsef.org. I look forward to hearing from you!

- Sue Carneol, MS, CCC-SLP
VCFSEF Editor

WELCOME FROM THE PRESIDENT

Steve's Top 10 Reasons to Make a Vacation Around the VCFSEF 17th Annual International Scientific Meeting in Salt Lake City Utah



Steve Orton, President

I look forward to seeing you at our annual meeting July 16-18 this year. In the past, attendees and families have made a vacation around the conference. There is so much to see and do in our region. I want to share some of my suggestions as you make your travel plans.

1. Visit Utah's National Parks.

With five national parks, Utah is America's national parks capital. Our parks include: Zion National Park, Bryce Canyon, Arches National Park, Canyonlands National Park, and Capitol Reef National Park. A visit to one or more of these parks is a "must-see." Bring your camera to capture the award-winning vistas. The best experience involves hiking but you can see some extremely amazing views from your car.



2. Experience Park City. It's a 30-minute drive from downtown Salt Lake City or just 20 minutes to shopping at the outlets. Park City is home to one of the longest slides in the world with over 3,000 feet of gliding and sliding down a luge-like track. Utah was home of the 2002 Winter Olympics with many exciting things to see such as the Olympic Park. Park City, the home of the Sundance Film Festival, is loaded with dining and shopping options galore. Some call Park City a suburb of California. You'll like it.

3. Take a hike. The trails in Utah are diverse and range from a casual-leisure hike to an extreme (must be physically fit) hike. Hike to a waterfall or on a ridge. Take in the beauty of the mountain or desert scenery.

4. See and hear the Mormon Tabernacle Choir.

This famous choir labeled America's Choir by President Reagan has a practice each Thursday night that is free to the public. Doors are opened at 8:00 pm and the rehearsal concludes at 9:30. The Choir's weekly live half hour broadcast Music and the Spoken Word is the nation's longest-running network program, having run continuously since 1929. The broadcast takes place every Sunday morning at 9:30 a.m. Those wishing to



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Welcome from the President

(Continued from page 2).

attend should plan to be in their seats by 9:15 a.m. If you can't see the Choir, Temple Square is Utah's top tourist attraction.

5. Go mountain biking. Utah has been labeled as the most geographic diverse state in the country. There's plenty to see and a great way to take it in is on a bicycle. See and experience the wide open desert, the beautiful red rock vistas, the magnificent lush green mountains with plenty of wild life and wild foliage. Utah has earned a world class reputation from Moab's famous Slickrock Trail and is fast becoming known for wonderfully diverse alpine mountain biking, including lift-served access at some ski resorts.

6. Discover your ancestry at the Family History Center. The largest genealogy library in world is one mile from the conference hotel. Stop in and receive genealogy help from experts for free.

7. See the wildlife at Yellowstone National Park. Yellowstone, located mostly in Wyoming, is a day's drive from Salt Lake City. This magnificent park should be on everyone's bucket list.

8. Drive to Grand Canyon to see one of planet Earth's most astounding natural features. Located in Northern Arizona, it's a day's drive from Salt Lake City.



9. Check out Timpanogas Cave. Timpanogas Cave National Monument sits high on Mount Timpanogas of the Wasatch Mountains. Three spectacularly decorated caverns in the cave contain helictites and anthodites which are just a few of the many dazzling formations to be found in the many chambers. As visitors climb to the cave entrance, on a paved trail gaining over 1,000 feet in elevation, they are offered incredible views of American Fork Canyon. If you have a free day I suggest that you consider hiking to the top of Mount Timpanogas which 11,749 feet above sea level. It's considered a Weekend Warrior activity, but I did it with my son who was 10-years-old at the time.



10. Tack on a Las Vegas Trip. As you plan your flight to Salt Lake City, you may save airfare costs by making a triangle trip with Vegas as one of your destinations. There's endless entertainment and food in Las Vegas.

- Steven J. 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 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.

MESSAGE FROM THE EXECUTIVE DIRECTOR



*Karen Golding-Kushner,
Ph.D.*

When Velo-cardio-facial Syndrome was first described as an entity by Dr. Robert Shprintzen, it was because he noted similarities among a number of children who had presented to a major craniofacial center. That was over 20 years ago, before we knew that the 22q11.2 deletion was behind the problems, and those children have now grown up. As our early patients have gone from childhood to adolescence to adulthood, we have had an opportunity to learn more about the “natural history” of VCFS. We have seen them overcome early obstacles, such as feeding and speech disorders, and have exciting accomplishments. We now know that, in spite of the challenges of getting there, normal eating, normal speech, and normal physical

growth are realistic outcomes. At the same time, we have seen that development and maturity sometimes bring new challenges in areas such as social development and psychological well-being. During the last several years there has been an explosion of research interest in understanding these challenges, and especially in identifying the neurological and chemical processes controlled by the brain that might predispose some people with VCFS to be fine and others to have more difficulty in these areas. This understanding is leading to more effective treatment. This issue of the Newsletter is centered on the theme, “Transition to Adulthood,” and some of these perplexing issues are discussed.

In keeping with the current interest in transitions to adulthood, we are planning several related presentations at our annual meeting in Salt Lake City this July. A highlight will be our panel discussion in which all participants on the panel are adults with the 22q11.2 deletion, aka VCFS. In addition, one of our “Lunch with the Experts” options will be a round-table for teens and adults with VCFS. Our expert panelists with VCFS will facilitate the conversation, but we hope that all of the teens and adults with VCFS who attend the meeting will participate in the lunch session.

We are excited to announce that a featured speaker at this year’s conference will be Dr. Dennis Ruscello. Dr. Ruscello is a speech-language pathologist with an interest in oral motor and sound system disorders including structural-based problems. He is a Professor of Speech Pathology and Audiology at West Virginia University and Adjunct Professor of Otolaryngology in the Department of Otolaryngology of the West Virginia University Health Sciences Center. He is a member of the WVU CED Feeding and Swallowing Team and WVU Cleft Palate Team. He has published over 85 manuscripts and presented approximately 130 papers to various professional groups. Dennis holds the Certificate of Clinical Competence in Speech-Language Pathology (CCC/SLP), is a Fellow of ASHA, and a member of the American Cleft Palate Craniofacial Association. He is widely recognized as an expert in speech disorders associated with cleft palate and velopharyngeal insufficiency.

Will you arrive in time for our Welcome Pizza-by-the-Pool party on Thursday, July 15 from 6:30 to 8:30 PM? Relax after your arrival in SLC to reunite with old friends and make some new ones! Then be ready bright and early Friday morning for the opening of the scientific and educational program.

Abstracts are still being accepted for review, and we encourage all of the professionals who have not yet done so, regardless of institutional affiliation, to submit your research for presentation. There is also a forum for presentations from families or people with VCFS and submissions can be made using the same form.

We were all horrified to hear about the devastating earthquake in Chile. I contacted Dr. Gabriela Repetto, a geneticist involved in VCFS research, who is our contact person there. I asked how they were and asked if they needed anything specific. Here is her reply:

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GOT TALENT?

Have you ever gone skydiving? We will show a DVD of a bold adult, who happens to have the 22q deletion, jumping out of plane, right after her husband!!! I won’t tell you who, but she will be at the meeting and the DVD will be shown at our first-ever Talent Showcase at the Optional Friday night dinner! (She also plays piano and may be the accompanist for her flight.)

Guess which world-renowned surgeon plays the drums? You will have to come to the dinner to find out. He’ll be performing live on our stage.

What world-class concert pianist teaches at a music conservatory and happens to have VCFS. Hint: she is mom to an adorable almost-toddler and is a member of the Council on our Board of Directors. I won’t name names, but we will be treated to hearing her play piano.

What’s YOUR talent? Professional and family members welcome! Kids and adults! Just go to our website to complete the form and volunteer to participate. You can perform live or on DVD.

Bring your cameras and we’ll see you on stage!

Message from the Executive Director

(Continued from page 4)

Dear Karen, thanks a lot for asking! We are doing well, and I understand that the families that live in Santiago are also safe. There is very limited communication with rural areas, so it may be a while before we have full info. Once we have a better sense of what is needed, I can let you know. Thanks a lot for asking!

*Take care
Gabriela*

A member of our Facebook group lives in Concepcion, Chile, close to the epicenter of the earthquake. He last posted on our FB discussion board on 2/23/10, just four days before the earthquake. I have not been able to reach him, and we hope he and his family are safe and out-of-touch only because of interruptions in communication.

Before closing, I wish to appeal to each of you reading this newsletter to support the VCFS Educational Foundation. Please become a member and be counted! Dues payments and donations are our only source of funding but we have ongoing expenses including the toll-free phone line, which helps hundreds of professionals and families reach us for information each year, the website, and the annual meeting. Registration fees cover less than half of the conference expenses. We are trying to keep the brochures available at no cost – but they are an ongoing expense and we have more languages waiting to go to print. Please consider making a donation. Any amount is welcome!

Thank you, and see you in Salt Lake City!

*- Karen J. Golding-Kushner, Ph.D.
Executive Director
March 4, 2010*

Note: I finally heard from our Facebook group member (3/8/10) near the earthquake's epicenter on March 8, who wrote, *"I'm fine. I'm working at the hospital to help people affected by the earthquake. Now The State and some private institutions are organized to give help to those places more affected. Thanks for writing."* We are relieved to hear this and continue to wish him, his family, and community well.

RESEARCH ROUND-UP

Editor's note: This new column for the VCFSEF Newsletter offers our readers information of research studies, projects and programs that have been recently completed, in progress, or are being planned. The VCFSEF does not fund or sponsor research, however, we are happy to publicize work in progress. To be included on our website or newsletter, the research proposal, protocol, and IRB approval must be submitted for review. Please send your request to executivedirector@vcfsef.org for review by the research committee .

Social and Sexual Challenges in Adolescents and Young Adults with VCFS

Doron Gothelf, M.D., The Behavioral Neurogenetics Center, Schneider Children's Medical Center of Israel and Middle East Regional Director

In a study of large cohorts of individuals with Velocardiofacial syndrome (VCFS) from Israel (the laboratory directed by Doron Gothelf) and from Western Europe (the laboratory in Switzerland directed by Stephan Eliez) we evaluated the rate of psychiatric disorders in VCFS from childhood to adulthood (Green et al. 2009). In this study we found a high incidence of depression (44%) in the group of young adult individuals with VCFS aged 18 to 24 years. From our clinical experience we think that the emergence of depression during young adulthood in VCFS may stem, in part, from a difficulty achieving the independence and social integration expected at that age. Our clinical experience also shows that for many individuals with VCFS, coping with the challenges of becoming independent adults (e.g., leaving home, finding a vocation and developing a stable affective relation with a person of the opposite sex) can trigger depression.

Other issues that are of major challenge to adolescents and young adults with VCFS are social and sexual issues. Adolescents with VCFS have the same needs, drives, desires and interests as other youth and go through the same changes – physical, emotional, and social. However, sexuality is a more complicated issue in people with VCFS, where the sexual component of growth is often denied by parents and care takers.

Parents of adolescents with VCFS often avoid the issue of sexuality as a result of fear: fear that talking about these issues would promote sexual interest, fear of embarrassing situations, fear of sexual abuse, pregnancy or sexually transmitted diseases. Parents are also influenced by the fear that their child with VCFS will inevitably transmit the syndrome to their offspring. Although there is a growing recognition of the need for parent consultation, only few receive guidance or education regarding sexuality of their child with VCFS. This lack of information about sexuality leads to a feeling of helplessness and to choosing dysfunctional ways of coping.

In our view, the recommended approach to help disabled children to develop their sexuality lies in educating both the adolescents with learning disabilities and their parents, providing them necessary information on sexuality.

While there is some increasing awareness of the need for psychosexual education in individuals with developmental disabilities, there is lack of awareness for this need in individuals with neurogenetic syndromes. At the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel we treat individuals with neurogenetic syndromes associated with learning disabilities including VCFS and Williams syndrome (WS). As we feel that social and sexual issues of adolescents with WS and VCFS are crucial for their development and well-being, we decided

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Research Round-up

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to conduct Social-Sexual Group Education Programs for adolescents and young adults with VCFS and Williams syndrome. The treatment program ran as two parallel groups: one for adolescents and the other for parents. While sexual education interventions for adolescents are conducted in special education schools in Israel, there is rarely any educational or therapeutic work being done with the parents. In our work with parents, we learned that they have grave difficulties accepting developmental changes occurring in their disabled adolescents. The parents expressed anxiety that their child will not be able to cope properly with their social and emerging sexual drive. In some cases the parental anxiety tended to strengthen mutual dependence, limiting the ability of the adolescent with developmental disabilities to develop social, sexual, and other skills needed to foster their independence as an adult. Parents exhibited shame regarding the sexuality of their children. They expressed fears that their child could be a victim of sexual abuse, unwanted pregnancy, and giving birth to a disabled baby. To induce a significant change in sexual and social maturation of adolescents with developmental disabilities requires long term work with the adolescent and, even more so, with his parents. In our view one of the main achievements of the group therapy was to provide some tools and justification for the parents to help their adolescent exercise their right to have a satisfactory social and sexual life.

To develop a safe and satisfactory social and sexual life, adolescents with genetic syndromes and developmental disabilities first need to acquire an adequate self-concept that requires knowing their abilities and accepting their limitations. Adequate self-concept leads to choosing a proper social relatedness group of adolescents with similar developmental levels. Only in such a social relatedness group can the adolescent feel equal and have true friendships that are based on reciprocal relations. In cases where the adolescent with a developmental disability fails to develop adequate self-concept, and chooses to associate with a group of typically developing adolescents, he/she may be predisposed to abuse and humiliation. The ability to establish intimate-romantic relations is the top level in this hierarchical pyramid relying on the establishment of proper self-concept and proper social group relatedness.

We are convinced that supporting adolescents and young adults with the developmental challenges as described in this article can help them in their brave struggle to become, a more independent young adult. This will consequently help prevent the occurrence of depression during the vulnerable period of transition to adulthood.

Reference: Green T, Gothelf D, Glaser B, Debbane M, Frisch A, Kotler M, Weizman A, Eliez S. Psychiatric disorders and intellectual functioning throughout development in velocardiofacial (22q11.2 deletion) syndrome. *J Am Acad Child Adolesc Psychiatry.* 2009 ;48:1060-8

GLOBAL FORUM

Editor's note: We are resurrecting the Global Forum which was a standing article for the VCFSEF newsletter for several years. The purpose of the Forum is to collect and archive ideas from the community around the world on important topics related to Velo-cardio-facial syndrome. Cheryl Dultz, a parent and educator, and Joel Stoddard, MD, served as moderators for the column. Last year, articles related to issues of young adulthood were solicited and are presented in this current issue of the newsletter given our theme of "Transitioning to Adulthood."

Social – Romantic – Employment Issues

As parents, our greatest hope is that our children will grow up to be happy productive citizens. This forum deals with the young adult's issues of friends, life partners, and employment. We are grateful for the many submissions and hope that our edits captured the essence of your stories. As we have all learned, there is no one path to adulthood for our children with the syndrome. There is, however, a reoccurring theme in all of the narratives – education and advocacy almost always meet with success. We hope these stories will shed some light on the adult issues of romance, friendship, and employment.

Our sincere thanks go to the families who shared their experiences with us
~Cheryl Dultz & Joel Stoddard

A mother from Australia wrote about her "almost" 27year old son who was diagnosed with VCFS when he was 13. She stated that "We always knew something was a bit different with him and years of trying to find out finally paid off."

High school was not easy for him, but he went to technical college and did a few different courses. His first job was as a car detailer, washer and yard person. He continued doing this same type of work

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Global Forum

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for different car yards for about 6 or 7 years. He was able to save money, buy himself a car, and get his driver's license. He currently works in a factory and recently got his fork lift license of which he is very proud. His mother wrote that he has never left a job because he didn't like it-- he stuck with it regardless. Regarding his romantic life, his mother wrote that he has had a girlfriend for the last four years, which helped his self esteem. Her son continues to have challenges with reasoning and planning ahead.

The mother of a 24 year old woman with VCFS, who lives in Ireland, shared her frustration in trying to connect with other parents of young adults with the syndrome. The support group in her area was comprised mostly of parents of younger children. The mother shared the concerns she had regarding her daughter, Aine's, social, vocational and romantic challenges that she faced in her transition to adulthood. The mother questioned if it would be more advantageous to inform employers and potential friends about VCFS to help allay potential misunderstandings about Aine. The mother stated that these issues are complex and complicated and it was difficult to know how to handle them.

Another mother writes that her 20 year old daughter with VCFS has had significant problems with social interactions, affecting her social, vocational and romantic experiences. After high school, Meghan went to college taking regular college classes. She was able to use the bus system to get from home to school and back.

Meghan considers herself very social and most of her social endeavors have centered around church activities. The mother described Meghan as "persistent" in her own efforts to interact with peers her age. At times she has been successful and other times not. Mother stated that Meghan can be outspoken and literal, citing that "neither (trait) bodes well with relationships".

Meghan's mother shared her frustration with Meghan's limited insight into her own social difficulties as well as Meghan's difficulty maintaining a part time job. Meghan recently met a young man who was very much like she was. Her mother expressed concern over the young couple's talk of marriage and their ability to function independently with finances and other responsibilities.

The mother of 24-year-old Forrest shared some of his successes and challenges as he transitioned to adulthood. She indicated that enrolling her son in a private school in 6th grade proved to be an excellent decision despite the financial burden. She felt the public school could not meet Forrest's needs. The private school setting allowed him to socialize with other children with similar needs, minimizing negative effects on his self esteem. After graduating high school, Forrest stayed on at the school to be an aide. He then began a job training program at a residential state facility through the Department of Rehabilitative Services. His mother wrote, "It was so hard to leave him there but in the end turned out to be beneficial to him. He thought he was at college. In addition to doing very well studying computer technology, he met a girl who is still his girlfriend three years later. It is so great that they met and that they have each other. It is heartwarming to see them together. They both seem to light up in each other's company."

Forrest's mother described her son as a "people-person" who tries hard to have connections with others. These connections come from either relatives, people he meets online playing video games, or people from the center. She stated that he always got along better with adults and has had several in his life who have taken great interest in him.

In closing, Forrest's mother wrote that she has had to keep a watchful eye on her son and his environment, making sure he had the best opportunities he could. She added that she continues to struggle with the fear of how the "real world" will treat him.

"A mother's intuition is a strong thing" wrote Patrick's mother as she reflected on her young adult's life. She sensed something was not quite right and began questioning his primary care doctor when her son was 1 1/2 or 2 years of age. Patrick's speech was not developing as it should. The mother was reassured that all children reach their milestones in "their own good time." When Patrick was 3 1/2, he was finally referred to a speech-language pathologist, who referred the family to a speech and hearing clinic where Patrick's was diagnosed with hypernasal speech. The family also learned that he might have a syndrome called "Shprintzen Syndrome." After several surgeries to correct his velopharyngeal insufficiency, Patrick was diagnosed with VCFS. The future was uncertain. Patrick was nearly 5 years old by that time. No one could tell the parents whether or not he would have severe learning disabilities. No one could tell them about the future of Patrick's mental health, which, according to the mother, is one of the most frightening manifestations of VCFS for the parents.

Patrick always loved his father's computer at work. When the parents found out about the diagnosis, a computer was bought for the home and the mother's research began. No one had heard of VCFS in their small town, so the mother's lifeline was through the computer. She found a listserv and made quick friends another mother of a child with the syndrome. Their children were close in age and the mothers communicated regularly with each other. It was reassuring to know that there was someone else going through many of the same challenges.

The mother said that she, on her own, learned about speech, occupational, and physical therapies, as well as sensory-integration, and hippo-therapies. She educated the doctors, teachers, and therapists as she and the rest of the family were learning. Through this process she realized that she had to strive for the best outcomes and work at avoiding the worst.

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Global Forum

(Continued from page 7)

Patrick learned to work hard at a very early age. Today, at age 19, his mother still describes Patrick as a hard worker. All of his teachers have commented on his strong work ethic. Patrick learned the violin and was in the school orchestra from grades 5-12. Patrick graduated with honors from high school this past year with plans to attend college in the fall. He hopes to earn his bachelor's degree in Multimedia. His mother knows that with his work ethic and determination, he will achieve his goals in life.

Learning all she could about VCFS helped Patrick's mother. She researched interventions, accommodations and modifications that would help her son in the classroom. She learned to be "the expert" and the best advocate she could be. She came prepared to all IEP meetings, armed with articles that substantiated things that would help Patrick be successful. The parents encouraged him to join Boy Scouts, play sports (until it became too competitive), and learn a musical instrument. Patrick's orchestra experience helped him socially as he befriended other orchestra members. Patrick was also active in church activities. According to his mother, Patrick was a "fun loving kid". However, he never quite understood the rules that govern social relationships. He did not know how to interact in an age-appropriate manner. At 19, he is doing much better, but still has to be reminded from time to time. By involving Patrick in structured and adult monitored social situations, he learned how to interact more appropriately.

The family was involved in Patrick's school and extra curricular activities. Both parents were PTSA officers at school, as well as classroom volunteers. They developed strong relationships with his teachers and principals. They were scout leaders and youth group leaders, as well as "cheerleaders" for Patrick. Their involvement allowed them to see Patrick's behaviors, learn his strengths and weaknesses, and see how he interacted with his peers and superiors. Together, the parents developed plans that would best serve Patrick.

When asked what they may have done differently, the mother reflected that she

would not have spent so much time worrying and placing him under a microscope. She said, "I would try to take more pleasure in today and worry less about tomorrow. Parenting a child with special needs is not easy. It takes work and patience. But, there are many wonderful things that you learn along the way. You learn that we are not supposed to fit in the same cookie cutter mold." Patrick's parents believe that their knowledge and involvement were keys to their son's success.

Professional Response from USA

By: Kevin M. Antshel, Ph.D.
Assistant Professor of Psychiatry
Department of Psychiatry and Behavioral Sciences
SUNY - Upstate Medical University
Syracuse, New York

As a child psychologist (and a parent of two), I am reminded daily that one goal of parenting is to help insure that our children become comfortable, confident and self-sufficient adults. The stories detailed above describe clearly the challenges that are very common in parenting a child with special needs, VCFS or otherwise (e.g., ADHD, learning disability, etc.). In fact, all of the stories described above are rather non-specific to VCFS. In other words, these stories may be representative of many young adults, not just VCFS.

Much research has focused on how best to insure that children develop to become comfortable, confident and self-sufficient adults. While educational success (e.g., learning to read and comprehend, learning history facts, etc.) is important, in and of itself, academic successes are a rather poor predictor of which young adults will become comfortable, confident and self-sufficient adults. Thus, for parents of youth with VCFS, I often encourage parents to not exclusively focus on school and academic-related pursuits. Rather, developing peer relationships and fostering self-esteem are as important (if not more important) towards predicting functioning in early adulthood.

In regards to peer relationships, having one strong peer relationship is better than having many "acquaintances."

ANNUAL INTERNATIONAL SCIENTIFIC MEETINGS OF THE VCFSEF:

- July 16-18, 2010 Salt Lake City, Utah, USA
- July 2011 New Jersey, USA
- July 2012 Pittsburgh, Pennsylvania, USA
- July 2013 Dublin, Ireland

Thus, I encourage parents of youth with VCFS to focus on helping to identify same-age peers that may be that strong peer relationship. Youth with VCFS often respond far better to structured peer activities. Thus, these peer relationships may be best realized in the context of a club or group (e.g., Boy Scout, Basketball team) rather than expecting the youth to develop these relationships within an unstructured activity (e.g., playing during recess at school).

Self-esteem is a global term referring to an individual's self-opinion. Much research suggests that having skill in one domain is especially important towards self-esteem development. Thus, I also encourage parents of youth with VCFS to focus on identifying skills / talents which may provide gratification and serve as a tool for improving self-opinion. In other words, rather than focusing on strengthening weaknesses, focus on further strengthening strengths.

In sum, the above stories are highly representative of parents of youth with VCFS. In many ways, parents of young adults with VCFS are vanguards, raising a child with a genetic syndrome largely unknown to teachers, medical professionals, etc. We are all indebted to their tireless efforts. Many of these challenges, however, are not specific to VCFS. Developing one strong same-age peer relationship and further identifying and developing areas of strength (rather than focusing on improving weaknesses) may be important towards insuring the development of a comfortable, confident and self-sufficient young adult with VCFS.

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MEET REBECCA...

(Editor's note: Rebecca contacted the VCFSEF president, Steve Orton, after discovering our website on her internet research quest. Steve thought she is someone we would all like to meet.)



Hi! My name is Rebecca Crutchfield Osberg. I have been married to my wonderful husband, Tim for 11 1/2 years. I am from a small country town in Alabama: population about 3,200. I was recently diagnosed with VCFS/* DiGeorge and I would like to share my thoughts about this experience.

As a child I was sick a lot and needed to be hospitalized. I remember spending time in an oxygen tent and sometimes getting up to nine shots a day. Over the years I struggled with many different illnesses (asthma, diabetes, sinus infections, low calcium, low parathyroid) as well as some mental health issues. My speech sounds hypernasal. I knew something was wrong, but I just did not know what. I love computers and this led me to do research on the internet. This is how I came across DiGeorge. After the diagnosis was confirmed, one of my doctors told me I was a "walking miracle." This may sound strange, but I was excited and relieved about the diagnosis. I finally got closure.

As a child, I lived in the same town I live in now. I come from a family of faith. My parents had foster children over the years so we had a large family at times. We never did without. The best memories I recall were camping, vacations, and holidays. I was also a member of Girl Scouts and 4-H for

Global Forum

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Professional Response from Australia

By: Linda Campbell, PhD
NH&MRC Research fellow & SHIP Project Coordinator
University of Newcastle Priority Research Centre
Brain & Mental Health
Newcastle, Australia

Raising a child with a genetic syndrome is a challenge. It is often not enough to simply parent their child, parents often have to be advocates for their child/ren and teach health and educational professionals about VCFS. The process of searching for answers and raising awareness of their child's uniqueness often starts long before the diagnosis of VCFS. Initially the focus often is on life threatening complications of VCFS but as time goes and the child grows up new challenges come along. The school start is one of those stages with possible learning difficulties and social problems. Adolescence, which is a challenge for any parent, is another such stage when some develop mental health problems.

But at the stage in life when most parent-child relationships forever change and the child becomes an independent adult, the implications of the long-term outcomes of VCFS is at the forefront of many parents (and children's) mind. The question of 'how will my child cope by himself/herself?' becomes very pressing. Unfortunately, there has not yet been much research on this stage in life from a VCFS perspective. However, it is likely that the experiences by young adults with VCFS are not dissimilar to other people with special needs. Many young adults with special needs remain at home for longer and also remain financially dependent of their parents (however, this is becoming more common among all young adults!). The role of the parent may in fact become even more important as the young adult moves from the highly structured educational system into the workforce. This may particularly be true for people with VCFS with less intellectual disabilities since they may have higher expectations placed on them with less support in place. This can result in higher levels of life stress and challenges as they are trying to manage the transition to adult roles.

All parents would like their child to be a happy, healthy and successful adult. In order to achieve this, it is important to focus on building up self-esteem, coping skills, social ability and supportive social networks. It is also important to focus on the strengths and abilities of each person instead of focusing on the problems and limitations. As a mum of two young children I realize this is something that all parents need to work on but how do you actually do it? Dr. Antshel has provided some ideas with regards to peer relationships and self-esteem. It is also important to allow time for identity exploration to encourage independent thought, free choice, and give the opportunity to consider various occupations. These processes are, perhaps, more important in the successful transition to adulthood than traditional measures of adulthood. When accomplished in the presence of a supportive network, they provide the young adult with more tools to cope with future challenges as a happy, confident and independent young adult. In sum, parents continue to be an important support for their young adult with VCFS, as they are for any young adult. However, it is also important to ensure that external support resources (such as advisors, mentors, and friends) remain and are strengthened during this time to ensure that the youth has a good foundation for learning, to acquire life skills and explore his or her own possibilities.

several years. I started piano lessons at the age of 12. The most difficult thing I endured as a child was learning disabilities. I had trouble understanding the basic concepts of math, especially counting money. My dad worked with me

long hours. I struggled for a C average. Despite this, I received one award for most outstanding student in health occupations my sophomore year in high school. After high school, I went to nursing school and

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Meet Rebecca

(Continued from page 9)

got my license. I consider graduating nursing school and my marriage to be my biggest accomplishments. My patients have said that I am a very caring and compassionate person.

My current hobbies are playing the piano, writing poetry, sign language, and crocheting. I have surprised my friends and family at how well I do at all of them. I received a letter from President George Bush a few years ago for writing a poem for the troops overseas and I was on local TV. My current challenges are managing a budget and keeping a balanced checkbook.

My strong faith keeps me going. I now have a new goal: To establish a support group in Alabama for people with VCFS and their families. If you are interesting in joining, please contact me by email at mro121@ymail.com. You can also contact this or other support groups around the world by going to http://www.vcfsef.org/support_groups/index.html.

**Executive Director's note: Some doctors erroneously diagnose DiGeorge as a syndrome although it is actually a developmental sequence, not a syndrome. DiGeorge has many different genetic and non-genetic causes, and the 22q11.2 deletion, which is known as VCFS is but one of the many possible genetic causes. (DiGeorge Sequence refers to the association of congenital heart disease with hypoparathyroidism, hypocalcemia, and immune deficiency.) We left the use of the term as Rebecca wrote it so we would have the opportunity to include this explanation, as our mission as a Foundation is to educate both the public and professional communities.*

FREQUENTLY ASKED QUESTIONS

Question: My 24-year-old son has VCFS, something we only found out about recently because of some issues with depression. Although he struggled through high school and was never very active socially, he always loved music and our school system had really terrific music programs. He plays all types of percussion instruments and also plays keyboard instruments. When he is playing music, he is really happy and is well accepted by fellow students, but he always seems to be odd man out in classes, at lunch, and after school. I really want him to go to college, and many schools would probably love to have a musician like him in their marching band. Since he graduated from high school, he has had a few jobs, but never stayed in them too long. I tend to think that his bosses didn't understand his personality very well. We have never told anyone about him having VCFS, and we never really spoke with him about it either thinking that it would hurt his self-esteem. Do you think we should push him to go back to school so he might be qualified to get a better job?

Answer: (by Robert Shprintzen, Ph.D.): This question points out a lot of issues that require addressing, including education, your son's ability to "fit in" and adapt socially, the potential for depression, and counseling him and others about VCFS. Let's see if we can draw all of these together. Let's start with the "need to know" about VCFS. My personal opinion has always been to get the information out there. Externally, such as with educators, doctors, and other professionals who have contact with your son, the diagnosis has meaning and can affect treatment and courses of action. There are special aspects to management that the diagnosis provides. The diagnosis also provides opportunities for access to services that might not otherwise be available. For example, in schools, the diagnosis qualifies the student for the category of "Other Health Impaired" entitling them to special services and annual IEPs (Individualized Education Plans). The diagnosis tells doctors what problems to look for in order to intercept them before they become serious. Internally, in terms of telling your son and your family, I would have to ask if you think he has never been curious about his situation, or if you think that others close to you (friends and family) would somehow shun

him if they knew the diagnosis. The opposite might actually be true. When he is acting in a particular way that might be a part of the syndrome's phenotype, they may actually be thinking that it is something that he chooses to do, or something that you passed on to him. My own experience is that when people have an explanation, they immediately become sympathetic and curious to know more. When it comes to people with VCFS, I always advise people to let their curiosity be a guide for when to tell them. Enlist the services of a genetic counselor or other professional to help you if you feel lost in knowing what to say or what to do. The truth is usually the best option, but it needs to be told in a way that it is understood by your son and in a way that is relevant to his circumstances. The knowledge may help to relieve you and your son of guilt, defensiveness, and isolation. Should your son wish to start a family of his own some day, he will certainly need to know.

The issue of education, particularly as it relates to school and the day-to-day management of school work and achievement is highly variable in VCFS,

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Frequently Asked Questions

(Continued from page 10)

but primarily in relation to the process of getting people with VCFS through school successfully. There has been some material published on the process, how to manage IEPs, and how best to teach children with VCFS. Reading these materials is valuable, but I also like to advise people to focus on the bigger picture. Whether successful or unsuccessful, struggling or not struggling, isolated or not, at some point in time, school ends. The rest of life is then in front of you. I advise people, especially after elementary school, to try to “look with long eyes.” If the only approach is to get the child through school, then what happens? I prefer to focus on how education can prepare the child for the rest of life. What is the long-term goal? The learning disabilities in VCFS often means focusing so intently on the child’s problems, that the child’s strengths become overlooked. In your son’s case, the strength was music. Not only was it a strength, it was a source of happiness. How can you capitalize on that strength? How can his skills be put to good use in finding his place in this world so that he wakes up in the morning looking forward to his day? Obviously, without knowing more about your son, it is difficult to say what this will translate to, but it is a good starting place. It is a good idea to find those strengths, and there can be many in people with VCFS, and turn them into a path of opportunity, whether academic, vocational, or as an avocation. This may also be the means for having him “fit in” better because he will be likely to find other people with his same interests. In other words, guide him along the path he wishes to follow, not the path that you think the typical 24-year-old should follow. Stated another way, let’s not jam a square peg into a round hole. College may not be for him, but some other educational opportunity might be. There are now many vocational opportunities for people who would not benefit from the typical college path. Although some people with VCFS do go to college and can be quite successful, this is not true of all people with VCFS. Of course, the same can be said for people who do not have VCFS.

Finally, the challenge with depression and other psychiatric problems with VCFS is to determine how much of the problem is derived from an internal state, and how much from external stressors. Depression can also be a part of some of the endocrine problems that people with VCFS might have, such as hypothyroidism. The assessment of the nature of the problem is obviously dependent on getting appropriate evaluations and treatment. It is not necessarily simple, but this is one of the goals of the VCFS Educational Foundation...to provide you with as much information as possible so that you (and your son) can ask the right questions to your health care professionals.

REGIONAL UPDATES



Bronwyn Glaser, Ph.D.
Co-Regional Director,
Europe VCFSEF

Europe

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

Hi to everyone from the Old Country where we are having one of the snowiest years we can remember! We have received reports from our French and Irish Associations:

President Frédérique De Clercq writes that Génération22 is going through a real communication renaissance. For starters, they now have eight reference centers for treating VCFS and other genetic disorders in France. Each center is directed by a geneticist and is linked to the other reference centers, as well as to twenty centers where families can seek consultation. Génération22 is collaborating with each of the eight centers to organize meetings for families and health professionals. Meetings

have already taken place in Dijon, Lille, Lyon, Rennes and Paris, and will soon take place in Marseille, Montpellier and Strasbourg. The meetings are intended for parents who live far from Paris to be in contact with competent health professionals who work with the syndrome, and to help parents understand their own role in their children’s care. Gen22 is also working on a national protocol that will help set standards of care for treating VCFS. It will be accessible to all doctors and patients. In addition, they have organized a meeting to address some of the more difficult issues for families, including psychiatric issues, fertility issues for parents with the syndrome, and how to react when the microdeletion is detected during pregnancy. They are also publishing a regular newsletter and have 150 members on their Facebook page: GENERATION 22. All of these attempts in increasing communication hope to improve care for individuals with the syndrome and while providing information to circulate between health care providers and families. Gen22 is

working to keep affected individuals from feeling isolated by bringing the information to their closest city center.

Irish President Anne Lawlor writes: The 22q Ireland group had a very successful conference back in Oct '09. We were extremely pleased that both Bob Shprintzen and Stephan Eliez were able to join us, and of course, our families said it was the best one yet! May I take this opportunity to publicly thank them both - their visits made a visible difference and we hope they enjoyed their time here with us. ;



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Regional Updates

(Continued from page 11)

In more general terms we are slowly but surely increasing awareness for both of our groups: VCFS / 22q11. I have been giving some parental perspective talks to various people. There are plans in place for a new children's hospital here in Dublin and our hope is that we will have a designated care-coordinator for our 22q families operating from the new hospital.

European Rare Disease Day took place this year on 28th February. Here in Ireland we marked the occasion on Thursday the 25th February. The focus was on parents and professionals working together on research and of course on a National Plan (www.eurodis.org for more information). Professor Kieran Murphy who is currently conducting an Irish FMRI study presented his perspectives and then I presented as the representative of a parent-led support group.

In the midst of all this, we are planning this year's conference, some Family Days, keeping an eye to 2013, when we will host the 20th Annual International Scientific Meeting of the VCFS Educational Foundation and hoping to muster up the energy for Coventry in July! We also have a Facebook page now which is proving quite popular. On a much sadder note we lost one of our babies just before Christmas, little Billy. There is a very poignant link to a blog on the same FB page.



Antonio Ysunza, MD, SciD
VCFSEF Regional
Director Latin America

Latin America

Antonio Ysunza, MD,
SciD
VCFSEF Regional
Director Latin America

(editor's note: this was submitted a month before the devastating earthquake in Chile).

About a 1000 more brochures in Spanish were sent to Chile, Dr. Repetto, a geneticist of the Medical School of the German Clinic in Santiago,

will distribute them among families and professionals from Santiago and its surrounding areas.

This March, Dr. Ysunza will be in Cochabamba, Bolivia evaluating a patient with VCFS as well as presenting on the syndrome. The aim of these talks will be to increase awareness of Velo-cardio-facial syndrome and to help the patient's family start a support group in the area. Some of the plastic surgeons practicing in Cochabamba were trained in the Gea Gonzalez hospital in Mexico City and know of Dr. Ysunza's reputation. They will help promote the event. The VCFSEF Spanish brochures will also be distributed.

The last newsletter (January 2010) was translated into Spanish and is available to view on the VCFSEF website (www.vcfsef.org). From Latin America. Saludos a todos !!!



Dianne Altuna
US/Canada Regional
Director

US/Canada

Dianne Altuna
US/Canada Regional
Director

Fort Worth, Texas is hosting the annual American Cleft Palate and Craniofacial Association (ACPA) meeting March 15-20 of this year. Dianne

Altuna is the on the planning committee and will be presenting at the international conference where she will promote ongoing education and awareness of VCFS.

The Family Support Network in Wisconsin will host its annual family education event on May 1, 2010 in Milwaukee. Quinn Bradlee, accomplished author and documentarian who has VCFS, will be the speaker, sharing his experiences growing up with VCFS and learning disabilities. All are welcome to the event which will include social networking opportunities for adults and children. Please contact LuAnn Weik, genetic counselor at Children's Hospital of Wisconsin, for further information (414/266-2031 or lweik@chw.org).

In keeping with the season, new support groups are "springing up" around the US. A new support group is being formed in Alabama, spear-headed by Rebecca Osberg. You can read her story in this edition of the VCFSEF newsletter. Please contact Rebecca at mro121@ymail.com or 205-698-9923 if you are interested in joining the group.

Indiana has a new group, as well, headed by Courtney Wallace, a social worker with a 9 month old daughter with VCFS. She will be posting future meeting dates on the VCFSEF website soon and looks forward to sharing ideas, stories, and positive thoughts with those who want to join. She can be reached via email at court_msw@yahoo.com.

To contact these or other support groups around the world, go to http://www.vcfsef.org/support_groups/index.html

MEET MORE OF THE BOARD



Linda E. Campbell, PhD
Council, professional

Linda Campbell was born and raised in Stockholm, Sweden but went to London in the United Kingdom to study Psychology at the University College London and the Institute of Psychiatry. She started her research on VCFS as a PhD student in 2000 and is currently a post-doctoral research fellow at the Centre for Brain and Mental Health Research at the University of Newcastle in Australia. Dr Campbell is very interested in developmental psychopathology and is interested in following children with the syndrome from infancy to adulthood. She started doing her research on the relationship between brain, behavior, and cognition in children and adolescents with VCFS. Currently, there are a number of projects running in her lab including a study looking for precursors of psychosis in young people with VCFS, the development of social cognition in children with VCFS, and the transition to adulthood in young people with the syndrome. She can be reached at linda.e.campbell@newcastle.edu.au.



Merav Burg-Malki
Council, Professional

Merav Burg-Malki is the psychologist of the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel. She has been working with families with VCFS and Williams syndrome since the center was established by Dr. Doron Gothelf 8 years ago. As a part of her clinical work she is involved in the psychological evaluations and the diverse therapies that the center provides (Behavioral modification, Psychotherapy, Parent guidance, Social-sexual education program). She coordinates 'The Big Brother Program' that operates in their center, a program that helps children develop social skills and adaptive functioning. She is also the editor of the VCFS Israeli newsletter. She completed clinical child psychology training at Tel Aviv University and today is a PhD scholar (Israeli President Award) at the Psychology Department, Bar-Ilan University. Her research topic is social cognition and social behavior of children with VCFS and Williams syndrome. You are welcome to contact her at: 972-542456-110 or at meravbu@hotmail.com. Congratulations to Dr. Merav Burg-Malki on the recent completion of her doctoral degree!

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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**

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

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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 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

For questions regarding wrist bands, contact 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. 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.

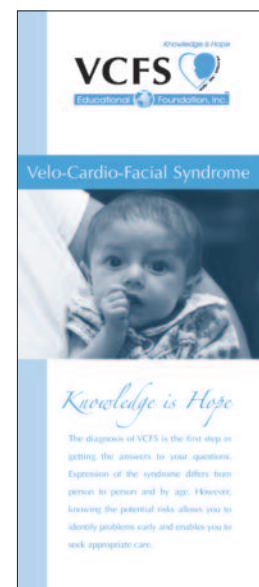


Knowledge is Hope brochure

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.

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