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2ND ANNUAL WALK FOR AWARENESS

Walk Around The World: A Global Feat To Raise Awareness of Velo-Cardio-Facial Syndrome

February 10 and February 11, 2012



Join the VCFSEF for our 2nd Annual Walk for Awareness. This year, we hope to make tracks across the world by walking in our local communities nationally and internationally. Let's not only walk in shopping malls, but also in parks. Our friends in the Northwest, Northeast, Canada, and Europe, who experience cold weather in February, may want to take advantage of those indoor shopping centers that cater to "mall walkers". Those of us in milder climates can meet at a park to walk and raise awareness. Either way, this is a great way

to meet others in your area and support a great cause. Checkout our Facebook page (<http://www.facebook.com/#!/groups/120247201099/>) or our website(www.vcfsef.org) for updates on where others are gathering in your area and for registration information.

VCFSEF is proud to offer new t-shirts for this event. Check out our website for a preview of this spiritwear. Receive a t-shirt for each registration of \$22.11. You can also ask friends and family to sponsor the "walkers" in your family.

Thank you for your support of the Walk for Awareness campaign and its goal to raise awareness of Velo-Cardio-Facial-Syndrome.



Tennessee Mall Walkers, 2011

[Click Here to Register Online!](#)

Questions? Contact Dianne Altuna at info@vcfsef.org for more information

Renew Your VCFSEF Membership Today!

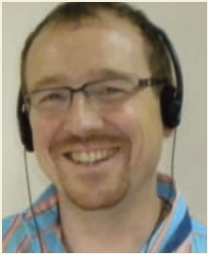
Membership renewal (Annual membership goes from January-December. Please be sure to renew your membership for 2012 by going to link below or by completing the form on the back.

http://www.vcfsef.org/support_foundation/memberships.html



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GREETINGS FROM THE PRESIDENT



Philippe DeClercq
VCFSEF President

As the festive season draws to a close, I would like to take this opportunity to wish you a New Year full of joy and happiness. Our world is, indeed, going through a period of uncertainty but - always the eternal optimist - I'm sure that, with the right outlook, we can all get the most out of what it has to offer.

2011 was a turning point for the VCFSEF. I'd like to thank Karen Golding Kushner and Dianne Altuna for the smooth hand over of responsibilities, which was essential for our Foundation to successfully move forward and face the challenges that lie ahead.

2012 will not be short of highlights, but perhaps the most exciting event on the calendar will be our annual meeting in Toronto, Canada from July 19 to 22. I was fortunate enough to spend a few days in Toronto and I can assure you that it is truly a venue of choice: a dynamic city on the banks of Lake Ontario, with an appeal - cultural, geographic and sportive - second to none. And, of course, a visit to Niagara Falls, whose roaring majesty will remain with you for years to come is a "must-see". I sincerely hope to meet as many of you as possible at this year's conference which, needless to say, will be extremely interesting. Experts throughout the world continue

to devote their time and their expertise to help us better understand and come to terms with the syndrome in our daily lives.

Please allow me to pay a special tribute to Christine MacDonald who, alongside her husband, works tirelessly to ensure that our annual meeting is always a huge success. I am in constant admiration of her devotion, from the very early stages of organization, right up to the final event.

On this point, things are starting to move in Europe for Micro Deletion 22q11. The parents' associations on the old continent are extremely dynamic and I am always amazed at the courage and dedication of all our volunteers. A great many meetings between families and medical personnel have been held in Belgium and Switzerland during the past few months, and a 2-day conference is scheduled to take place in Paris, France. This conference, organized by Génération 22, will bring together Europe's most eminent VCFS specialists. Rest assured that I will provide you with an update on the progress they are making in a forthcoming Newsletter.

For now, with the magic of the holiday season putting a refreshing smile on our children's faces, let us take heart in this symbol of hope for all of us, children and parents alike.

I wish you all a very happy New Year.

19 THINGS TO DO IN TORONTO

By: Christine and Brad MacDonald,
Local Arrangement Chairs

We are very excited about the Scientific Meeting coming to Canada in 2012. A venue has been secured and the local arrangements committee is busy working on fundraising activities and working out the details of the event.

Given 2012's meeting will be the 19th Annual International Scientific Meeting for the Educational Foundation we thought it might be appropriate to let you know about 19 things you could do in Toronto area.

1. **Toronto Zoo** - Divided into geographic regions, the zoo's 710 acres feature more than 5,000 animals in their natural environments. A fun filled day can end in the Splash Island, an exciting two-acre water play area.
2. **Centre Island & Centreville** – Only a 10-minute ferry ride from the foot of Yonge Street, the Toronto islands offer an amazing panoramic view of the city skyline. Centre Island offers miles of parkland with beaches, barbecues and picnic tables, boat rentals, bicycle paths, and Centreville, a children's amusement park.
3. **CN Tower** - Recently nominated one of the Seven Wonders of the Modern World, the CN Tower features glass floor observation decks, a revolving restaurant, and a Simulator Theatre. It is Toronto's most recognizable landmark.



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19 things to do in Toronto

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4. **See a show** – Toronto is the third-largest theatre centre in the English-speaking world, after New York and London with over 90 venues in the greater Toronto Area. Many theatres are in beautiful historical buildings which add to the theatre experience.

5. **Shopping at the Eaton Centre** - The Eaton Centre, is a multi-leveled, glass-roofed galleria comprising more than 320 shops and restaurants, 17 cinemas, and a 400-room Marriott hotel. Even if you are not a shopper it is a great building to see.



6. **Ontario Science Centre** - The Ontario Science Centre offers interactive and multi-media exhibits with live demonstrations and exhibits on topics that include sports, space, the environment and the information highway.

7. **Historic Fort York** –It is a great place for people looking to have a good time and learn something about Toronto's rich history. Some highlights of your visit would include a guided tour highlighting the lives of soldiers and officers at Fort York; Fort York Guard demonstrations every hour and cooking demonstrations (and tastings) as well as museum exhibits.

8. **Canada's Wonderland** - Canada's Wonderland is home to the most exhilarating collection of rides (68), roller coasters (15 thrilling ones!) and water park fun in all of Canada. For the younger kids — Planet Snoopy; Charlie Brown, Snoopy and the Peanuts gang welcome kids of all ages.



9. **Catch a Blue Jay's game at Rogers Centre** - Famous for its retractable roof, the Rogers Centre is home to the Toronto Argonauts football team and the Toronto Blue Jays baseball team.

10. **Cinema under the stars** – This is somewhat of a summer tradition in Toronto, when the sun sets open-air movie theatres pop up all over the town. Many of them are free and most locations are once a week for the entire summer.

11. **Art Gallery of Ontario (AGO)** – It has just recently been announced that the Art Gallery of Ontario has secured a blockbuster Picasso retrospective from Paris. The show that is currently on a seven-city world tour, will have its exclusive Canadian presentation at the AGO for four months starting in Spring 2012. Perfect timing for the meeting attendees.

12. **Royal Ontario Museum (ROM)** – The Royal Ontario Museum is among the world's leading museums of natural history, and of world cultures.

13. **Shops at Don Mills** - This is where fashion, dining and entertainment come outside to play. This is Ontario's first and finest open air centre with exceptional shops, restaurants and services surrounding a lovely Town Square.

14. **Distillery District** – This is a great part of Toronto that includes many shops, restaurants, art galleries and even a brewery. This area of Toronto was created by a group of developers whose vision was to combine the romance and relaxing atmosphere of European walking and patio districts with the hip, cool dynamic of an area like New York City's SoHo or Chelsea. A very trendy place to visit.

15. **Ontario Place** - As Toronto's number-one destination for family fun, Ontario Place offers hours of entertainment and over 30 rides and attractions including a water park and Cinesphere, home to the world's first permanent IMAX® theatre.

16. **Harbourfront** - Toronto's downtown waterfront has gradually been transformed into a lakeside people place. The heart of this revitalization is the award-winning Harbourfront Centre - the site of art galleries, theatres, craft boutiques restaurants, offices, hotels and marinas fronted by a waterside promenade.



17. **Bata Show Museum** – The museum celebrates the style and function of footwear with hundreds of shoes on exhibit. Who wouldn't want to visit this???

18. **Casa Loma** - The former home of Canadian financier Sir Henry Pellatt, Canada's foremost castle is complete with decorated suites, secret passages, an 800-foot tunnel, towers, stables, and beautiful 5-acre estate gardens



19. **Black Creek Pioneer Village** – Take a trip back in time as you tour the village and learn about how the Pioneers used to live. You will be able to see buildings and artifacts from this time period as well as become immersed in the lifestyles, customs, and surroundings of early residents.

We really hope you are able to join us for the 2012 conference in Toronto. We also hope you are able to see some of the amazing things Toronto has to offer.

FROM THE EDITOR'S DESK



Sue Carneol, MS,
CCC-SLP

Happy 2012! It's that time of year when we make resolutions to do better in the months ahead. To help in that cause, the theme of this newsletter is "Prevention". Articles cover a wide range of topics from preventing tooth decay to anxiety. One of the best ways to prevent a potential problem is to be informed. The Velo-Cardio-Facial Syndrome Educational Foundation's primary mission is embedded in its name: Education. This newsletter, our website, educational pamphlets in a variety of languages, and webinars are among our educational tools. However,

the crown jewel of our efforts is the annual International Scientific Meeting held each summer. This summer we will be congregating in the international city of Toronto in Ontario, Canada from July 19-22. As you begin to make summer vacation plans, consider planning around this family-friendly meeting. In this newsletter you will find 19 great reasons to vacation in Toronto and the Niagra Falls area. Speaking of the International Scientific Meeting, this newsletter features a few of our notable presenters from this past meeting in New Brunswick, New Jersey. To read their entire presentations, you can visit our website (www.vcfsef.org) and click on the Members section to access the handouts and Power Points from the meeting. Not a member? It is easy to join on-line at the website or send us your membership application found in this newsletter. Membership perks include reduced registration at the meetings, access to informational resources and presentations, and knowledge that your donations support continuing public awareness and education about VCFS. Highlights of additional fundraising opportunities for this coming year are featured in this issue. We appreciate your continued interest and support of the VCFSEF as we delve into new ways to meet our mission in the year ahead.

WRAP FOR AWARENESS 2011

I concluded 25 hours of gift wrapping at my local Barnes and Noble Bookstore on December 19, 2011. Over the 25 hours, I met incredible people, and told everyone about VCFS, and the Educational Foundation. I know I increased awareness of this syndrome among medical professionals, educators, parents and grandparents.



Over \$450.00 of donations were made to VCFSEF through Wrap for Awareness. This money will be directed towards new t-shirts for the 2nd Annual Walk for Awareness on February 10 and 11, 2012. You can register now for the walk at vcfsef.org.

While December 2012 seems to be a long time away, please consider organizing your own Wrap for Awareness in your local community.

Happy Holidays to All!

Dianne Altuna
VCFSEF Executive Director

USING HYPNOSIS TO HELP PEOPLE WITH VELOCARDIOFACIAL SYNDROME

By: Ran D. Anbar, MD

Professor of Pediatrics and Medicine, SUNY Upstate Medical University, Syracuse, NY President, American Society of Clinical Hypnosis

Individuals with velo-cardio-facial syndrome (VCFS) can face many psychological challenges. For example, anxiety is common among these individuals, and includes children with fears regarding interacting with their peers or dealing with new situations, as well as children who are afraid of being separated from their parents. Also, attention-deficit/hyperactivity disorder is thought to affect more than a third of adolescents with VCFS.

Because of behavioral features of VCFS, many children have difficulties with daily living skills and social interactions, which lead them to be rejected by their friends, and to become socially isolated. Many children with VCFS develop low self-esteem because

of these difficulties. Furthermore, as children become older, their psychosocial difficulties tend to worsen because of the increase in what is expected of them socially and academically in school.

How can hypnosis help?

A basic hypnosis anxiety reduction technique can be taught in 10-15 minutes during a visit with a health care provider such as a family practitioner, internist, pediatrician, psychiatrist, psychologist, or social worker. Once individuals learn how to use self-hypnosis they can help reduce their own anxiety that can occur in reaction to

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Using Hypnosis to Help People with Velocardiofacial Syndrome

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psychosocial stressors. For example, children who become anxious in social situations can use hypnosis to become calmer, which allows them to interact more easily with their friends.

Patients also can use hypnosis to reduce discomfort associated with medical procedures. For example, an 8-year-old patient with VCFS needed to undergo a magnetic resonance imaging (MRI) scan and was very scared by the loud noise made by the scanner. His physicians thought about using general anesthesia in order to allow the test to take place. Fortunately, once he learned how to apply hypnosis he remained awake and calm throughout the 10 minute test, and felt very proud of himself.

Thus, learning how to use hypnosis provides people with a new coping skill that they can use whenever they wish. As a result of their successes, people gain self-esteem. Further, they can learn to give themselves helpful hypnotic suggestions to improve their confidence and good feelings about themselves.

What is hypnosis?

Even experts in hypnosis have not been able to agree on a definition. When I work with children I tell them that hypnosis is a fancy word that describes how they can use their imaginations to help themselves.

Hypnosis is not an unusual condition. How often has a driver of a car had the experience of not remembering the last 3 miles of a trip? Where has his or her mind been? This is an example of hypnosis. Whenever children engage in imaginary play they are doing hypnosis. Thus, children are naturals at hypnosis.

Contrary to popular perception, hypnosis is not sleep, although it can be a wonderful tool with which people can help themselves fall asleep, stay asleep, and even improve sleep experiences such as nightmares, sleep walking, or bed wetting.

Finally, hypnosis does not involve placing the patient or client under the control of a "hypnotist." All hypnosis is self-hypnosis. It only works when a person wants to become hypnotized.

One definition of hypnosis accepted by many people is that it involves an altered state of consciousness in which people become more suggestible. For example, if a person is anxious and is told, "Calm down," his or her response might be, "I can't calm down. If I could, I would have already." On the other hand, when the same individual is in hypnosis, and calmness is suggested, typically the response is in agreement, and the individual calms down.

An example of simple hypnosis to help with anxiety involves telling a child to think about a favorite place, and to imagine what he or she might perceive with all of the senses there, which helps make the experience seem more real, and therefore more relaxing. The child then is taught to access the same feelings of relaxation when he or she needs to become calmer.

Hypnosis works better initially when working with a health care provider, and therefore should not be applied just by reading about it in a book or this article.

Are there alternatives to hypnosis?

Therapies that help individuals feel better about themselves can be as useful as hypnosis. For example, counseling, meditation, Reiki, and yoga all can be helpful. However, these other therapies typically are provided outside of the office of the primary care provider, and often require multiple sessions. On the other hand, for many individuals, hypnosis therapy can be completed in only 1-3 sessions.

How can someone best learn to do hypnosis?

The best way to learn about hypnosis is to work with a health care professional who has been trained by a professional society of hypnosis such as the American Society of Clinical Hypnosis, the Society for Clinical and Experimental Hypnosis, or the National Hypnosis Pediatric Training Institute.

One way to find a health care provider in your area who has received professional training is to consult the website of the American Society of Clinical Hypnosis at www.asch.net. Another way is consult with your primary care provider for a referral.

To learn more about hypnosis, consider reading *The Complete Idiot's Guide to Hypnosis -2nd Ed.*, by Dr. Roberta Temes, which was published by Alpha books, 2004. Interested health professionals who work with children can consult *Hypnosis and hypnotherapy with children – 4th Ed.*, by Drs. Daniel Kohen and Karen Olness, which was published by Routledge, 2011.

MESSAGE FROM EXECUTIVE DIRECTOR



*Dianne M. Altuna,
VCFSEF Executive
Director*

Winter Greetings to All! 2011 is officially over, and with it, so many ways to raise awareness of VCFS through community, national and international events. Thank you to each of you who developed, worked, and participated in these events.

2012 will also include events to raise awareness. We begin, in February (2/11/12 and 2/12/12) with our 2nd Annual Walk; "Walk Around the World: A Global Feat to Raise Awareness of VCFS". Join other families at malls and parks around the US and World to raise awareness of VCFS. We have great looking long sleeve t-shirts for sale on our website (www.vcfsef.org).

Also, in February, Christine, Brad and Emma MacDonald (host family for the upcoming VCFSEF conference in Toronto, Canada) will be holding a "Read-A-Thon" at Emma's school. All proceeds from this event will go towards the conference in Toronto, Canada. Christine is a great source for ways to raise awareness in your community. Please feel free to contact Christine if you are interested in developing an awareness campaign in your area.

Our largest event to raise awareness and provide education regarding VCFS is our 19th Annual International Scientific Meeting, July 19-22, 2012 at the Hilton Toronto Airport Hotel. The program committee is hard at work, with areas of focus on: "Transition into Adulthood"; "Social Cognition across the Ages" and "Immunology" topics. Christine MacDonald and her Local Arrangements Committee are working on activities for the children, and the Friday night gala. I would like to extend a personal welcome to everyone to attend this meeting. It is an incredible way to be informed about the recent developments in research; interact with professionals from around the world; and meet others with family members with VCFS.

I'd like to end with a challenge to each of you to raise awareness of VCFS in your community, beyond your family, child's school, and physicians. Each year, I teach a course at the University of Texas at Dallas in the Department of Communication Disorders. Fall semester of 2011, I had 44 students, 42 of these students had not heard of VCFS until they attended this course. Ashli Cheung agreed to come to the class and speak about having a child with VCFS. Her presentation and honest responses to questions provided the students with an experience they will never forget.

Each of you can contact colleges, universities, medical schools, nursing schools, speech pathology, education departments, occupational therapy programs and a variety of other programs in your area and ask to present information about VCFS. You have the power, as parents, and individuals to increase the knowledge of VCFS in your community. Let's make 2012 a year of increased awareness of Velo-Cardio-Facial Syndrome.

Warmly,
Dianne Altuna, M.S./CCC-SLP

BUYER BEWARE!

By: Sue Carneol, MS, CCC-SLP, VCFSEF editor

When I was a child, my parents needed to buy a new washing machine. They went to the local appliance store where the salesman helped them select the model that best suited their needs and budget. Many years later, when I needed to buy appliances for my first home, I poured over consumer magazines to get the most current product reviews, which were based on reputable consumer research. Only a few years ago, when I needed to replace my refrigerator, I went "online" to comparison shop. Today, all you need is a "smart phone" with an app that lets you scan barcodes to instantaneously bring the best deals to your fingertips. With this kind of technology, how many of us would only rely on one salesperson's recommendation for the purchase of a new car, large appliance, or computer? Not too many. If only there was an app to help us evaluate and determine the best educational, mental health, and/or medical intervention for us, our children, or family member.

Today we are constantly bombarded with direct-to-consumer advertising on television, radio, and print ads in magazines. This form of advertising tells us which prescription medication we should tell our doctor to prescribe, or which program or item we should use. Some of the direct-to-consumer advertisements feature a celebrity's personal experiences to help sell. Social networking sites provide us with some of the more trendy or frequently used interventions or products that might be helpful for us. However, it is important to realize that this "well meaning information" is not objective. It is based on anecdotal accounts versus good scientific research to assess the efficacy and validity of these products and programs. Most of us rely on professionals to use evidence-based practices when determining which services, programs, or supports are needed to improve function and quality of life. The use of Evidence Based Practice (EBP) has become an important variable for medical, mental health, developmental, and educational professionals when defining standards of care. My professional organization, The American Speech-Language-Hearing Association (ASHA) defines Evidenced Based Practice as

...the integration of: (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver values to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve. (<http://www.asha.org/Members/ebp/intro/>)

What role do we, the consumers, play when medical, early intervention and school team members ask us to weigh in and agree to proposed interventions? We, both service-consumers and service-providers, should take the role of

Skeptic. At the 18th Annual International Scientific Meeting of the Velo-cardio-facial Syndrome Educational Foundation (New Brunswick New Jersey, July 15, 2011), the keynote speaker was Dr. Gregory Lof, department chair and professor of the Communication Sciences and Disorders program at Massachusetts General Hospital in Boston. He opened the meeting with a thought-provoking presentation entitled, "How to Determine if a Therapy is Based on Science." During his talk, he defined the terms pseudoscience, quackery, and skepticism as follows:

Pseudoscience: A pretend or spurious method or as having the status that scientific truths now have.

Quackery: A type of pseudoscience; any practice or remedy that has no compelling scientific basis for them to work. It includes questionable ideas, products, and services regardless of the sincerity of the promoters.

Skepticism: An approach to accepting, rejecting, or suspending judgment on new information that requires the new information to be supported by evidence. Therefore a skeptic is a person who has a questioning attitude or has some degree of doubt regarding claims that are elsewhere taken for granted.

Dr. Lof outlined "common thinking errors" on the part of consumers that persuade us to disregard scientific information. A few examples include

- "We are more likely to be persuaded by personal experience and anecdotes than by objective statistical evidence."
- "We prefer evidence that supports our beliefs and ignores or downplays evidence that questions them."
- "We are prone to ignore the role that chance events play in our everyday lives and, instead, erroneously assign them to causal status."

Dr. Lof discussed ways to avoid being "quacked" and how to detect "baloney." He offered useful tools for using skeptical, yet critical thinking in our decision making. He shared "Tools for Skeptical Thinking" from a book by Carl Sagen (1996, *The Demon Haunted World: Science as a Candle in the Dark*, New York: Random House):

1. Independent confirmation: has research been done by sources not directly related to the product or program?

Buyer Beware!

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2. Encourage debate on the evidence
3. Believe data not “experts”
4. Spin more than one hypothesis
5. Don’t overly attach to a hypothesis
6. Quantify the findings
7. Every link in the argument chain must work
8. Count the hits and the misses
9. A case study is not experimental
10. If it is too good to be true, it probably is NOT true.
11. Determine if the information obtained followed the scientific methodology
12. Be wary of information from the popular press

If you did not have an opportunity to hear Dr. Lof’s presentation at the VCFSEF Annual meeting in July, I encourage you to go to the “Members” section on our website (www.vcfsef.org) to obtain the handouts from his talk as well as handouts and PowerPoint presentations from the other notable speakers. If you are not currently a member of the VCFSEF, this is one great benefit of joining. A Membership application is included in this newsletter or can be found on our website.

As a seasoned speech-language pathologist, I found Dr. Lof’s presentation empowering. Over the years I have witnessed the comings and goings of a variety of intervention programs – some based on solid, peer reviewed research, others based on less rigorous studies, and some based on anecdotal reports. For example, some of the current trends in speech and language therapy that could fall in the category of quackery include oral motor therapy and blowing horns and whistles to remediate speech production deficits and/or improve velopharyngeal function, Auditory Integration Therapy to ameliorate attending and listening comprehension difficulties, and dietary supplements to improve speech motor planning difficulties. Again, as professional and lay consumers of therapy programs, it is important to exercise the above mentioned “skeptical thinking” strategies. There is an abundance of scientific evidence showing the lack of efficacy of these procedures, yet some unsuspecting consumers get sucked into these procedures by persuasive providers.

At the beginning of this article I lamented for an “app” that would help choose appropriate therapy options, but it is important to realize that even a published “app” may not have been subjected to critical standards of validity and efficacy. In this world of instant information access, the buyer must beware! It behooves us all to do further research into the program and its authors. With healthy skepticism, we can become better informed and educated consumers for whatever is being offered.

THERE’S NO PLACE LIKE A MEDICAL HOME

By: Jack Levine, MD

“Every child deserves a medical home” is the motto of the American Academy of Pediatrics (AAP). Nothing could be truer for children with Velo-Cardio-Facial Syndrome (VCFS). Care from specialists is critical, but community based family centered, preventative and coordinated pediatric care is the key to the health of all children and especially those with special health care needs. Now, don’t go looking for that perfect “Medical Home” – there is no such thing! According to the AAP, “a medical home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician whom they trust. Pediatricians and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential. . . where care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent.”

Above all else, the medical home is community-based. Children with VCFS should get care near where they live just like their brothers and sisters and neighbors. Care is family-centered, based on trust and mutual responsibility. The family is recognized as the center of strength and support for the child and it plays a central role in care coordination and decision making. Specialists may be at various locations and distances, but the place where the doctor and family come together for discussion and decisions should be close to home. The health care provider (HCP) knows the family and can help make important decisions. This is especially important when there are multiple medical options and during transitional times (such as Early Intervention to the Committee on Preschool Education (CPSE)).

The child is treated as “a person” and all their needs, medical, educational, developmental and psychosocial, are addressed. In other words, they are treated like children first and not just children with VCFS. Especially important to families of children with VCFS is coordinated care. The medical home can help to develop a plan and to coordinate care among the many providers in the lives of children with VCFS. By having knowledge of relevant community services and systems of support, the medical home helps with referrals, finding consultants, support groups and family resources.

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There's No Place Like a Medical Home

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What are some of the barriers to this type of medical care? Insurance companies usually do not adequately pay HCPs for the time that they spend with families to deliver this care. This is true in spite of the recommendations of Bright Futures which is a blueprint for optimal primary care published by the AAP. Many parents are their own case managers and care coordinators. When health care providers help to share that responsibility it can involve phone calls, referrals, multiple discussions with families and specialists and filling out forms...forms...and...more forms. Some families have trouble getting adequate insurance and often have limited options on where and how to receive care. This is becoming more and more common as states deal with their financial crises.

VCFS is a complex and "relatively" uncommon condition. Recently, HCPs have been encouraged to improve care for the more common chronic illnesses like asthma, obesity, autism and ADHD. There are many nuances in the care of children with VCFS (such as when and if a gastrostomy tube is needed, velopharyngeal functioning and the timing and type of ENT surgery) that may be difficult for HCPs to understand; they may not have seen many children with VCFS and need to learn more. Once informed, they can begin to successfully coordinate care and act as advisors. Studies show that pediatricians are willing and able to help families with complex conditions BUT they need information. Families can provide their HCP with helpful information from sources like VCFSEF.

Parents and other professionals can help HCPs become a medical home and partner with them to provide support and advocacy! Two good resources are www.medicalhomeinfo.org from the AAP and www.familyvoices.org. Some suggestions include communicating with office staff about your special needs and how best to minimize waiting time in the office. Bringing a list of your top questions or concerns is helpful and saves time. If you get nervous or time is short, you can show the list to the HCP. A notebook (or the digital equivalent) that holds children's health information is an important tool so that all material is easily accessible. All involved professionals can help keep this up to date. Included in this notebook, can be a written care plan (made in conjunction with the HCP and specialists) that outlines management for important health issues. It is best (and less confusing) to have health care information for children with VCFS in one location so have all reports sent to the medical home.

Children and families with VCFS need and deserve a "Medical Home." In these times it will require the cooperation and collaboration of families and all caring professionals to champion this critically important health care concept.

SPINNING FOR VCFSEF

By: Christine MacDonald



Members of the Local Arrangements Committee (LAC) for the 2012 Annual Scientific Meeting helped raise \$4,800 in pledges at a Spin-A-Thon event held on November 19, 2011. This event involved 42 people riding spinning bikes for an hour each. Teams of 4 were asked to raise pledges of \$200 as a team and our participants far exceeded our ask! While raising money for the VCFSEF scientific meeting that will be held in Toronto from July 19-22, this year, we also helped raise awareness of VCFS. We handed out a number of Educational Foundation pamphlets and fielded questions from other patrons of the gym. The event also included a craft sale and bake sale for our hungry spinners. The local arrangements committee would like to thank GoodLife Fitness – Market Square for the donation of the space and bikes; Kaufman YMCA for the donation of passes as incentive prizes to the individuals who raised the most pledges; and Pioneer Park Pharmacy for assistance in obtaining protein bars for all of our riders. The following people were the top 5 in terms of pledges raised: Brad MacDonald - \$675 (LAC member); Jennifer Thompson - \$390 (LAC member); Marlene Anderson - \$370; Claudia Hall - \$280 (LAC member); Jennifer Gruber - \$268. Our next fundraising opportunity is holiday donations in lieu of gifts to teachers, coaches, therapists, etc. Check out the Educational Foundation website at www.vcfsef.org for information on how you can make these special donations for the holidays. Every dollar gets us that much closer to our goal.



DENTAL HEALTH AND YOUR CHILD

James F. Mulick, D.D.S, M.S.

Editor's note: Individuals with VCFS are prone to dental problems due to poor tooth enamel, problems with tooth shape and size, number of teeth and/or time of tooth eruption. Because of this, parents need to be aware of steps that can be taken to prevent the progression of tooth decay and other issues.



Dental problems in children with Velo-cardio-facial Syndrome have early beginnings... often due to things as simple as allowing a night bottle of milk or juice at bedtime once those baby teeth start coming in; offering the "harmless" lollipop in the supermarket; or even waiting until age 3 or 4 to start teaching tooth brushing.

Tooth and gum care is not instinctive like a bird's first flight. It is a learned function and must start early with small steps to be successful. Begin with a wet washcloth and simply wipe those first two lower teeth. Start once a day, work up to twice a day, then finally after any meal. Next introduce the small, soft bristle toothbrush. The amount of any toothpaste should be VERY SMALL. The size of a pea is enough for a whole set of baby teeth.

Remember that many children with VCFS have difficulty learning new tasks or have muscle weaknesses...we need to go slowly with lots of repetition and PRAISE!!

RUNWAY SHOW AT THE AVEDA INSTITUTE OF BEAUTY AND WELLNESS EXPERIENCE

By: Tessa Koller

(Editor's note: In last spring's VCFSEF newsletter, we met a remarkable young woman who was diagnosed with Velo-Cardio-Facial Syndrome as a young adult. Tessa Koller is a fashion designer who is writing a book about her life's experience growing up with numerous medical, psycho-social and educational challenges. When I met her and her mother last February at the Milwaukee Walk for Awareness, I was impressed with Tessa's poise and artistic talents. I asked her mother, Margie Koller-Podjasek to share how she was able to foster her daughter's unique talents to help her through some of life's challenges as well as cultivate potential vocational opportunities. Now, almost a year later, Tessa shares her personal success story which evolved due to her mother's love and support as well as keen foresight and preventative efforts to build on Tessa's strengths, while minimizing her other challenges.

My name is Tessa Koller and I live with 22q11 Deletion, VCFS (Velo-Cardio Facial Syndrome) and heart disease. I am also a working artist, fashion designer, and CEO of my business Tess-Ko Designs. I live semi-independently in Milwaukee, Wisconsin. On Friday October 21, 2011, I had a runway show at the Aveda Institute of Beauty and Wellness in the city of Milwaukee. There were two showings, one at 6:30 and the next at 7:45 p.m. The room was filled with close to one hundred people. About nine photographers crowded the runway, seven of which work for me.



Tessa on the runway

colleague. We collaborate on advertising, marketing projects and expanding our professional networks. Two other photographers joined him for the runway show and they were responsible for the behind-the-scene photos. Another young photographer did set work for American Idol when they came to Milwaukee this past season and I do shoots with both of them every few weeks with several professional models.

In preparation of this show, I had to coordinate 15 models, fit them before they went on the runway and make sure they presented my clothes correctly. Though I had to work with 30 different schedules (including the photographers and

One photographer, who appeared on this past season of American Idol, is my business

Continued on page 11

Runway Show at the Aveda Institute of Beauty and Wellness Experience

(Continued from page 10)

directors at the Aveda Institute) I found ways beforehand to stay organized. I created an inventory list and idea in my mind about the image I had created for my clothes and the styling of the runway shows.

As the CEO of my business Tess~Ko Designs, I knew it was my responsibility to have documentation or an inventory list of all the work I produced. This not only protects the designer from having merchandise stolen, this also keeps the show going smoothly so every model knows what to wear and how to present. I knew what to do to remain organized, which allowed me to be calmer and go through the motions more smoothly. During busy, hectic events I found my organizational skills helped me slow things down and keep things as easy going as possible.

I had to model in my own show because a model from Chicago couldn't make it at the last minute. All of us models needed to change quickly into my outfits. We were rushing back and forth from the bathroom to the changing room, hurrying to get ready for the runway. My adrenaline was running high while I prepared for the runway walk and anticipated the audience in front of the runway. However, I found ways to turn off most of the anxiety. After taking several deep breaths, drinking lots of cold water and being prepared, I felt good and ready to take on the runway wearing my own hand-made designs. My models were very supportive, kind, and loving. I now understand the feeling they get when

performing for designers and photographers. Modeling is a form of acting, as you have to capture the style through a certain personality. This is what I had to do on the runway in front of almost 100 people, several photographers, and the news team from the local CBS affiliate in Milwaukee. It was overwhelming to stand in line hearing the audience roar and see lights flashing from a distance. Music was blasting through the speakers. The only thought that kept me calm was that all I had to do was walk a certain way and add swagger to my steps. I knew everyone was there to support me through the big event.

As I walked on the runway and saw my significant other, his family, and my family in the crowd, my nerves began to wash away. There was nothing scary or nerve-wracking about my event. In between shows, a reporter from the local CBS news interviewed me for about twenty-minutes. My message I hoped I communicated for that interview or to anyone who lives with VCFS/22Q11 deletion syndrome is this...

Focus on the things you can do and always work to improve what you feel you can't do. If you focus on the things you can do, then you just might end up in a high-end career like fashion design. However, it takes knowing how to manage your symptoms and listening to what your body really does and doesn't need. My mother always knew what I truly needed more than any other doctor. We both research extensively. We are always reading, learning, searching and advocating. It takes a lot of support from parents, your community and your network to reach success. Only YOU can stop you from achieving your goals!

REGIONAL UPDATES



Dianne Altuna
US/Canada Regional
Director

United States and Canada

On September 20, 2011, the VCFSEF sponsored its 1st Webinar on Cognition, Attention and Anxiety: Implications for Everyday. The "virtual seats" were quickly sold out and post webinar reviews were positive. Keep checking our website at www.vcfsef.org for more information about future Webinars.

Christine and Brad MacDonald (Host Family for 2012 Meeting in Toronto, Canada) sponsored a "Spin-A-Thon" over the weekend of November 9. More details on the results of this fundraising event can be found in this newsletter. Also in February, 2012, Christine and Brad MacDonald will sponsor a "Read-A-Thon" at their daughter's school. Not only will this raise awareness of VCFS, but, proceeds will again go to VCFSEF.

A "Wrap for Awareness" was held at the Barnes and Noble in Dallas at the beginning of December. This fundraiser raised awareness of VCFS in the community while providing beautiful wrapped books and gifts for a donation to VCFSEF.

The first "Holiday Gift Idea" campaign was kicked off for the 2011 Holidays. Generous donations were made in honor of family, friends, and teachers.

Our 2nd Annual "Walk for Awareness" will take place 2/11 and 2/12/12. Please visit www.vcfsef.org for more information on how to join this walk. Make plans to meet up with others at local malls and parks.

July 19-22, 2012 VCFSEF heads to Toronto, Canada for our 19th Annual International Scientific Meeting. Please make plans now to join us for this 2 ½ day informative meeting.

Continued on page 12

Regional Updates

(Continued from page 11)



*Antonio Ysunza, MD,
Latin America Regional
Director*

Latin America

Greetings from Latin America ! It has been a very interesting time for the Chilean VCFS Group. The School of Medicine from the Universidad del Desarrollo and the Chilean VSCF group hosted a scientific meeting this past November 7th in Santiago de Chile, South America. The topic under discussion was "Psychiatric Aspects of VCFS". The invited guest speaker was Dr. Anne Bassett. Dr. Bassett is a professor of psychiatry at University of Toronto, Ontario, Canada. She is also the director of the Clinical Genetics Research Program in the Clinical Research Department at the University of Toronto. Moreover, Dr. Bassett is the Canada Research Chair in Schizophrenia Genetics and Genomics Disorder. Dr. Bassett presented a theoretical lecture on the topic which was followed by an hour long question and answer period for parents and professionals. The group of parents were very appreciative of the information provided by Dr. Bassett, since in Chile, there are no experts in psychiatric aspects of VCFS.

The Chilean VCFS group is proud and pleased to continue providing educational programs for families and professionals. Thanks to the ongoing support from Dr. Luis Calvo Mackena Hospital and the Gantz Foundation, they anticipate future endeavors to promote the highest quality of care for individuals with VCFS.

Editor's note: Dr. Yzunsza thanks Dr. Gabriela Repetto and Mirta Palomares, SLP for providing the information found in this report.



*Dr. Linda Campbell, PhD,
Australia & New Zealand
Regional Director*

Australia and New Zealand

On the 3rd of December, a one day meeting for parents and professionals, "Experts Down Under", was held in Hamilton on the North Island of New Zealand (NZ). More than 40 parents gathered in there and another 10 attended via video links from Wellington, Christchurch and Invercargill. It was a day full of speakers with plenty of time for questions. The event was organized by Sue Haldane from Taupo with help from the organization Parent-to-Parent (who provided the conference room and the technical support with the video links). Speakers included Maeve Morrison with more than 30 years of experience as a speech and language pathologist.

Maeve has been involved in the VCFS family support group since the very first meeting NZ meeting in 1999. Another speaker who participated in that very first meeting was Dr Warwick Smith, an experienced general and developmental pediatrician from Auckland. Dr Smith wrote the first NZ life span management on how to manage the care of people with VCFS/22q11.2 deletion syndrome. In this meeting, Dr Smith offered advice on the role of the pediatrician in providing care for children with VCFS. Dr Glenn Bartlett, a consultant plastic surgeon with specialties in cleft lip and palate, offered information about surgical intervention in VCFS. Dr Nerine Gregersen, a pediatrician and clinical geneticist presented on the genetic basis of VCFS/22q11.2 deletion syndrome. In her day-to-day work, Dr Gregersen also focuses on long term family care and helping patients finding meaning in situations when faced with a genetic diagnosis. Dr Gregersen recently moved to New Zealand from South Africa. Dr Linda Campbell, an academic and research psychologist from Australia presented research findings from on-going studies from the University of Newcastle. It was a very successful meeting that will hopefully be followed by many more so watch this space!



Above: Dr. Warwick Smith

Below: Susan Haldane and Dr Linda Campbell



VCFS EDUCATIONAL FOUNDATION ANNUAL SCIENTIFIC MEETING IS COMING TO CANADA!

2012 will be the first time the conference has come to Canada and we are very excited! By bringing this conference to Canada we are creating an opportunity for our Canadian professionals to come together and allow families to develop relationships that may not have had the opportunity to otherwise develop. We are very proud to be the host family and working to make this conference a success. We are busy working on various fundraising activities to help with the cost of the conference. If you have any questions or comments about the local arrangements please contact Christine MacDonald at vcfs@live.com

In addition to hosting the conference each year, the VCFS Educational Foundation also works to promote awareness of VCFS. One way the foundation has decided to do this is through the sale of VCFS ribbon magnets. The proceeds of these magnets are going towards our fundraising for the 2012 conference. You can display these magnets on your car, your fridge, your desk at work or your tool box! By displaying this item you are helping to expand awareness. You can order this product through the VCFS Educational Foundation website at www.vcfsef.org or email Christine at vcfs@live.com.



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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.

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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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		<p>Opening Remarks and Keynote Address Welcome from the VCFSEF – <i>Karen J. Golding-Kushner, Ph.D., Executive Director, Christina Bush and Jennifer Stevens, NJ 2011 Local Arrangement Co-chairs</i> The VCFSEF: Present, past and future; <i>Karen J. Golding-Kushner</i></p>
		<p>The Genome and VCFS – Part I: Moderator: Alan Shanske When does a 22q11.2 deletion not cause VCFS? <i>William D Graf, Ryan Miller, Robert J. Shprintzen, Robert R. Lebel</i> Combined human and mouse genetic approaches to find genes for VCFS; <i>Bernice Morrow</i> Questions and Comments</p>
		<p>The Genome and VCFS - Part II: Tissue interactions during inner ear development are regulated by the VCFS gene <i>TBX1</i>; <i>Dennis C. Monks, Evan Braunstein, Bernice E. Morrow.</i> New directions in genome research; <i>Vandana Shashi, David Goldstein, Wendy R. Kates, Robert J. Shprintzen.</i> The prevalence of chromosome 22q11.2 deletions in 2,478 children with congenital cardiac malformations; <i>Peter Agergaard, Charlotte Olesen, John R. Ostergaard, Michael Christiansen, Karina M. Sorensen</i> Genetic Modifiers of Cardiac Outflow Tract Anomalies in Humans with VCFS; <i>Tingwei Guo on behalf of the 22q11.2 International Consortium</i> Phenotype to phenotype correlations: Using new data mining techniques to find associations with IQ and other clinical features; <i>Marcia Friedman, Nathaniel Mileta, Cheryl Roe, Dongliang Wang, Bernice E Morrow, Wendy R. Kates, Kevin Antshel, Anne Marie Higgins, Robert J. Shprintzen</i> Questions and Comments</p>
		<p>Speech Disorders: Clinical and Surgical Treatment Moderator: <i>Karen J. Golding-Kushner and Sue Marks</i> Early intervention speech services: effective or not? Panel session (<i>Dennis Ruscello, Eileen Marrinan, Sue Carneol</i>) Normal speech in VCFS: achieving the goal; <i>Karen J. Golding-Kushner</i> Questions and Comments Surgical Management of Hypernasal Speech in VCFS: results and complications from a series of over 100 consecutive cases; <i>Sherard A. Tatum III</i> Panel: What to do if VPI is detected early: surgery now or later, and which operation? <i>Sherard Tatum III, Robert J. Shprintzen, Virginia Dixon-Wood, Dianne Altuna</i></p>
		<p>Personal Success and Independence: Adults with VCFS - Moderator: Anne Lawlor Marriage and VCFS: a panel of successful adults with VCFS and their spouses; <i>Quinn and Pari Bradlee, Karen and Douglas Lindsay.</i> The Joys and Challenges of being a Parent, when the Parent has VCFS; <i>Karen Lindsay</i> VCFS Around the World; <i>Altuna, Campbell, Glaser, Gothelf, Natsume, Ysunza</i> Questions and Comments</p>
		<p>Dental, Orthodontic, and Craniofacial Issues - Moderator: Bob Shprintzen Longitudinal soft tissue and skeletal facial development in VCFS; <i>Michael Arvystas</i> Dental and orthodontic disorders and treatment in VCFS; <i>George Cisneros</i> Platybasia in VCFS; <i>Ariela Nachmany, Yehuda Finkelstein, Doron Gothelf</i> Questions and Comment</p>
		<p>Behavior, Psychiatry, Cognition, and the Brain – Part I: Moderator: Bronwyn Glaser Integrating cognition, emotion, and psychiatry for treatment in VCFS; <i>Tony J. Simon</i> The development of cognitive control in VCFS; <i>Heather Shapiro, Tony J. Simon</i> Questions and discussion</p>
		<p>Behavior, Psychiatry, Cognition, and the Brain – Part II: What happens to ADHD across time in children with VCFS? - <i>Kevin Antshel, Kaitlyn Hendricks.</i> Hippocampal volume and hormonal correlates of stress in children with VCFS; <i>Elliott A. Beaton, Kathleen Angkustsiri, Margie H. Cabaral, Yingratana A. McLennan, Ingrid Leckliter, Janice Enriquez, Tony J. Simon.</i> Spatial cognition impairments and possible atypical hemispheric connectivity in VCFS; <i>Frederick C. Bassal, Margarita H. Cabaral, Monika Farhangi Oskuei, Ling M. Wong, Tony J. Simon.</i> How coping skills affect symptoms of anxiety and depression in young adults with VCFS; <i>Elise Parson, Ulrich Schall, Linda Campbell</i> Questions and Comments</p>
		<p>Behavior, Psychiatry, Cognition, and the Brain: Interventions – Part I: Moderator: Tony Simon Computerized cognitive remediation in adolescents with VCFS: a preliminary report; <i>Wendy R. Kates, Kerri Tang, Lauren K.</i></p>

	<p><i>Sanderson, Matthew Kurtz</i> The effect of methylphenidate on prefrontal cognitive functioning, inattention, and hyperactivity in VCFS; <i>Doron Gothelf, Tamar Green</i> Intervention for social skills deficits in children with VCFS; <i>Carrie Bearden, Maria Jalbrzikowski, Jennifer Ho, Carolyn Chow, Chelsea Anderson.</i> Mentoring program as an effective psychosocial intervention to encourage social engagement in children with VCFS; <i>Merav Burg-Malki, Doron Gothelf.</i> Questions and Comments</p>
	<p>Behavior, Psychiatry, Cognition, and the Brain: Interventions - Part II: Self-Hypnosis to Reduce Anxiety in Patients with VCFS; <i>Ran Anbar</i> Web-based socio-emotional remediation for persons with VCFS; <i>Bronwyn Glaser, Danny Dukes, Sonia Martinez, Amélie Dubuc, Catherine Pasca, Stephan Eliez.</i> Should psychiatric treatment be aimed at symptoms or at the genome? <i>William D. Graf, Robert J. Shprintzen.</i> Questions and Comments</p>
	<p>Implications for School and Peer Relations - Moderator: Elliott Beaton Dealing with bullying and victimization; <i>Guest Faculty Tracy Vaillancourt</i> Focus on Math Interventions for Students with VCFS; <i>Donna Cutler-Landsman</i> Addressing Bullying and Social/Written Language through the IEP; <i>Yolanda Ortiz</i> Education Panel, Questions and Comments; <i>Donna Cutler-Landsman, Yolanda Ortiz, Tony Simon, Tracy Vaillancourt</i></p>
	<p>Medical Issues and Management – Part I: Moderator: Alan Shanske Increased Medical Interventions in Children with VCFS; <i>Emily King, , Kevin Stanford, Robert Hopkin, Howard Saal</i> Is Oral feeding in Children with Severe Medical Issues a Possibility? <i>Jill Mellow</i> VCFS Plan of Care; <i>LuAnn Weik, Stephen F. Conley, Adriane L. Baylis, Sue O. Carneol</i> Questions and Comments Family disclosure of a VCFS diagnosis; <i>Dana Faux, Sonja Eubanks, Vandana Shashi, Kelly Schoch</i> Panel discussion and Refreshments: Disclosure of Diagnosis; <i>Anne Marie Higgins, Bettsy Leech, Vandana Shashi , LuAnn Weik</i></p>
	<p>Medical Issues and Management – Part II: Scoliosis and its treatment; <i>Guest Faculty Steven Reich</i> VCFS and Pediatric Care- There’s No Place Like a Medical Home; <i>Guest Faculty Jack Levine</i> Questions and comments</p>
	<p>International Advocacy and Support Moderator: Dianne Altuna Texas Senate Bill 1612: inception to outcome; <i>Dianne Altuna</i> The Importance of VCFS Support Groups; <i>Maria Kamper</i> Being a VCFS Advocate: How one person can make a difference; <i>Karen Golding-Kushner for Raymond Tanner,</i> Concluding remarks; <i>Karen J. Golding-Kushner, Dianne Altuna</i></p>

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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

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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.

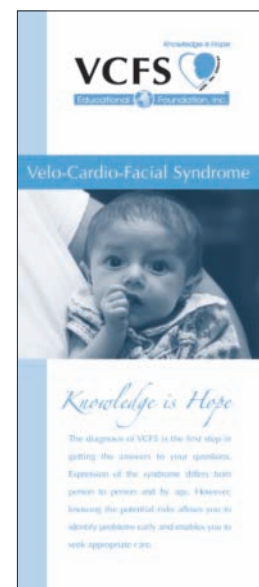


Knowledge is Hope brochure

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:

- Arabic
- Italian
- English
- Korean
- French
- Spanish
- Hebrew
- Japanese



DISCLAIMER

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

CONTACT INFORMATION

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

Telephone:

Toll Free 1.855.800.VCFS (1.855.800.8237)
From outside the US: 1-732-238-5494

Postal address:

VCFSEF
P.O. Box 12591
Dallas, TX 75225

Electronic mail:

General Information: info@vcfsef.org

Officers

Executive Director	Dianne Altuna	execdirector@vcfsef.org
President	Philippe DE CLERCQ	president@vcfsef.org
Secretary	Christina Bush	secretary@vcfsef.org
Treasurer	Jennifer Stevens	treasurer@vcfsef.org
Editor	Sue Carneol, MS, CCC-SLP	editor@vcfsef.org

Professional Council

Merav Burg-Malki	meravbu@hotmail.com
Virgina Dixon, Wood-M.A., CCC-SLP	woodgl@peds.ufl.edu
Alan Shanske, MD	

Lay Council

Karen Ruckman Lindsay	Ruckmankb@yahoo.com
Christine MacDonald	vcfs@live.com
Ashli Chung	ashli@momerize.com

Ex-Officio

Karen J. Golding-Kushner, Ph.D	Past Executive Director	kgkushner@vcfsef.org
Robert J. Shprintzen, Ph.D,	Past Executive Director	shprintr@upstate.edu
Steve Orton	Past President	ortonio@digis.net

Regional Directors

Asia and Africa	Nagato Natsume, DDS, D Med Sci., Ph.D	asia_africa@vcfsef.org
Australia and New Zealand	Linda Campbell	australia@vcfsef.org
Continental Europe (co-Directors)	Professor Stephan Eliez, MD	europe@vcfsef.org
	Bronwyn Glaser	europe@vcfsef.org
Latin America	Antonio Ysunza, MD, Sc. D.	latinamerica@vcfsef.org
Middle East	Doron Gothelf, MD	middle_east@vcfsef.org
United States and Canada	Dianne Altuna	uscanada@vcfsef.org