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Important News

Save the Date!

18th Annual International Scientific Meeting,
New Brunswick, New Jersey USA
July 14-17, 2011

July 2012 Canada
July 2013 Dublin, Ireland



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18th Annual International Scientific Meeting,
New Brunswick, New Jersey USA
July 14-17, 2011

Hyatt Regency in New Brunswick, NJ. Location of the 18th Annual International Scientific Meeting.

FROM THE EDITOR'S DESK



Sue Carneol, MS,
CCC-SLP

I am sitting in my family room right now with the windows and doors wide open, collating articles for the Spring edition of the VCFSEF newsletter. I am delighting in this first true spring day with warm sunshine, refreshing breezes, and soothing sounds of children playing outside. I live in the US Midwest and like for many of you, there have been numerous twists and turns to our weather this year, making life less predictable, sometimes scary, sometimes calming, and sometimes picture perfect! Today is really a breath of fresh air and I do plan on going out soon to enjoy it. As I finish up the last few edits, I am impressed. I did not start with a specific theme for this newsletter, but like the forces of nature, a theme evolved based on a pattern of topics from the various submissions.

This newsletter will spotlight, Family Matters. Many of us gathered on February 11 or 12 for our first International VCFS Walk for Awareness. The walk was a family affair and for many resulted in expanding their "family" support and resource networks. In this issue, you will meet a little girl with VCFS who was an inspiration to her family and others in her quest to bring in the most donations for the walk. You will read about a mother and her adult daughter who was recently diagnosed with VCFS, and how they were able to cultivate the daughter's talents to help her navigate her life's journey. You will meet a college-age sibling and the lessons she has learned from her younger brother with VCFS. Family matters in the world of Velocardiofacial Syndrome can be quite unique and challenging, but at the same time, similar to those experienced by any family. This issue offers advice from thumb sucking in young children to drug use in teens.

Continued on page 2

From the Editor's Desk

(Continued from page 1)

Finally, get out your calendars and mark down July 14-17 for a rewarding family vacation. Our 18th Annual International Scientific meeting will take place in New Brunswick N.J. There will be so many informational, social, and networking opportunities, not to mention all that awaits those who want to visit NYC, Philadelphia, or the Jersey Shores. Remember, our Kids Zone is open to ALL of our children – with and without the 22q deletion, children of faculty and children of all participants.

Experiencing today's weather in Milwaukee makes me realize that summer is just around the corner. Whether you are a professional, family member, or interested friend, make your reservations now for a remarkable gathering of hearts and minds this July!

- Sue Carneol, MS, CCC-SLP
VCFSEF Editor

1ST INTERNATIONAL WALK FOR AWARENESS

Dianne Altuna
Regional Director US & Canada

Walkers across the United States, France and Canada signed up to participate in the 1st International Walk for Awareness on 2/11/11 and 2/12/11. The event was held to increase awareness of Velocardiofacial Syndrome, and to raise funds for the VCFSEF. Proceeds from the walk will go directly to cover the costs associated with our 18th Annual International Scientific Meeting in New Brunswick, New Jersey, this July.

Awareness-raisers and fund-raisers ranged in age from young children to adults. The primary goal was to raise awareness and that was a rousing success with participants in four continents. Here in the US alone, we had walkers in 21 states. Fund raising was a secondary goal but was also successful with over \$5,000 raised. Congratulations to outstanding youth fund-raiser Amanda for raising over \$500.00 herself. Please read more about this amazing young lady in a separate article in this newsletter.

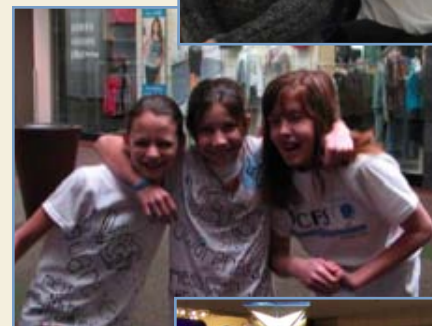
Thank you to everyone who participated either as a walker or a direct donor. Join me in thanking Nancy Robbins for sending out t-shirts and brochures to the registrants, and Cristina Bush for sending out acknowledgements for all donations. As in life, a team effort leads to the completion of ideas and goals. I was fortunate to have a great "Team" in reaching ours for this successful event.

Look for this Walk to be an annual event and enjoy the pictures from this year.



Wisconsin Group

Oregon Walkers



Lake Jackson Texas



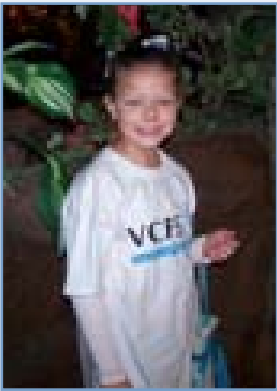
Tennessee Group

Greater Chicagoland Walkers



MEET ONE OF OUR YOUNGEST AND MOST SUCCESSFUL FUNDRAISERS

By: Ralph and Julie, parents



Amanda is 9 years old. She was diagnosed with 22q/VCFS shortly after corrective surgery for a submucous cleft at the age of 7 1/2. Amanda meets every challenge head on and we are proud of her strength, determination, empathy for others and sense of humor. The word "can't" is not in her vocabulary. Although she is aware that she has VCFS, she refuses to let it define her. She has participated in pageants, drama camps, science camp, sports, talents shows, Girl Scouts and loves to write songs and stories. She has a wonderfully positive outlook on life and has already made many differences in the world. She participates in many fundraisers every year, always thinking of others. Her most recent fundraiser really hit home as she participated in the VCFSEF International Walk for Awareness and surpassed her goal to raise \$500. She made many phone calls and sent e-mails to teachers, family, friends, and neighbors informing them she was participating in the walk and how VCFSEF helps to raise awareness and education. We are fortunate, and grateful to have supportive and special people in her life. She said, "I hope the money will help others and I love to walk in the mall!"

GREETINGS FROM THE GARDEN STATE!

Plans for the 18th International Scientific Meeting of the VCFS Educational Foundation, Inc. are well under way. We are looking forward to seeing everyone in New Brunswick, New Jersey July 14-17th, 2011. We hope you will consider making a family vacation around your trip to New Jersey. Our beautiful beaches and mountains await, as well as exciting New York City and Philadelphia within 60 minutes of New Brunswick.



We are very excited about all the Kidzone activities we have on tap...we certainly plan on keeping the children busy, happy and having fun. We welcome our volunteer Kidzone Supervisor Tammy Wall. She has lots to offer our little ones and we are busy coming up with entertainment as well. We are planning on having a visit from therapy dogs, face painting, a DJ, and even a player appearance from representatives of our local Women's Professional Soccer team, Sky Blue FC! There are sure to be lots of other surprises as well.

The children are our focus as the Local Arrangements committee, but we promise that the Program Committee is planning a full professional, scientific, and educational agenda, with speakers from around the world. 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. Among the topics will be the transition to adult life for people with VCFS with presentations on marriage and parenting by adults with VCFS. Please go to the Educational Foundation's web site (www.vcfsef.org) 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 the price of just \$99 per night.

Looking forward to seeing you in New Jersey!

– Jennifer Stevens and Cristina Bush

A BLESSING IN DISGUISE

By: Michelle Stalker

Editor's note: The following article was submitted by Anne Stalker, president of Mission 22q, a support group in Nebraska. Her 20 year old daughter, Michelle, wrote this composition for one of her college classes. Anne wanted to share Michelle's story about growing up with a sibling who has disabilities. Michelle now conducts workshops called "Sibshops", sharing her sibling perspective at local conferences.

My younger brother, Jeff, was born with DiGeorge syndrome, a microscopic deletion of the 22nd chromosome causing heart defects, cleft palate, learning disabilities, autism and OCD. Doctors had told my mom his entire life that there were going to be things he couldn't do, but she always focused on what he could, and in doing that he continued to prove those doctors wrong. He is now 18 years old and I couldn't be more proud of him. Without Jeff, I wouldn't have the drive that I do in my everyday life. He is the reason I have chosen my career path. I want to change the world for people with disabilities one day.

There are things in our lives that we cannot control and maybe things that we wish we could change; I think that those are the things that shape our personalities, make us stronger people, and allow us to see the world through another person's eyes. When my brother was diagnosed, I was too young to really grasp what was going on around me. I would say I was in denial because to me Jeff seemed like any other little brother, I didn't know any different. We still played together and fought with each other like siblings do. My mom and dad sat me down about a year or so later and explained to me that as he gets older there could possibly be things that he wouldn't be able to do and that we needed to, at all costs, encourage him to try new things. Even though I was so young I still took that to heart and made it my duty to protect him.

There were many times that I felt left out, like he was getting the bigger share of attention. In all reality he was. He had so many doctors' appointments, surgeries, trips to Omaha. There just wasn't enough time and energy for me at the end of the day. It left me feeling guilty a lot of the time because I would find myself blaming Jeff, but it was no one's fault. It has only been in recent years that I have been able to really come to terms with it and understand that they wanted to give me just as much attention as they gave Jeff but it just wasn't possible. We are definitely making up for lost time. Now I spend as much time with my parents as I possibly can.

While having a special needs sibling presents challenges, it also comes with opportunities. I have developed a large amount of patience, compassion and kindness. These are all traits that I use when I work with adults with developmental disabilities in their homes at Region V. I use the golden rule that we've all been taught since we were young, "Treat others the way you would like to be treated." We are all equal, we all make choices, and we all have the power to change the world for the better. If Jeff wasn't the glue that held me together, I would not be who I am today.



*Sibling buddies
Jeff and Michelle:
Then and Now*



TESSA'S STORY

Editor's note: I had the opportunity to meet a lovely young adult at our local VCFS Walk for Awareness in Milwaukee this past February. She was recently diagnosed with VCFS. Tessa Koller is a fashion designer, who just wrote a book about her life's experience growing up with numerous medical, psycho-social and educational challenges. I was very 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.

Margie writes,

Tessa is 26 years old. She is the youngest of my four children. At 11 weeks old she had open heart surgery. Although she was barely verbal and two years delayed in her overall developmental skills, she attended preschool for three years. At age six she transitioned to a self contained special education classroom, though a specific diagnosis had not been made.

This transition produced a great deal of anxiety for Tessa. Gone were her fun days of painting in preschool, as she entered an era of pencil and paper tasks and the need to learn new skills. She began experiencing nightmares, waking the household for several nights with shouts and sobs. I understood only that there was a mean cat that was hurting her. But she began producing several drawings over several days. Collectively, these told a story of a little girl taking her cat to the hospital for an operation. In clear detail the cat on the table was surrounded by doctors performing surgery with the girl looking on from the hallway. Tessa created a story board and two pages stood out. All pages had the cat moving through the experience. But in one, the cat had magically changed into the girl sitting upright on the table with her chest bandaged. The remaining story panels showed the happy girl taking her bandaged cat home. Tessa's nightmares stopped following the completion of the story pages she had created. I was amazed and kept her well supplied with pencils and paper after that. From that time forward drawing became her best tool in decoding the questions and answers of her experience living with DiGeorge Sequence/VCFS.

Tessa is an artist in all ways. She graduated from residential LD high school at the age of 20. Her post secondary plan was to apply to art school. In her application she wrote that art was her visual voice. She was awarded a four year scholarship to the Milwaukee Institute of Art & Design. At the age of 24, during her final semester before graduation, she received the diagnosis of Di George sequence/VCFS. At last a label for the multiple physical and mental health problems she had experienced throughout her life. This revelation created a significant subtext of reality for her as she had struggled to cope throughout her young adult life. She was painfully aware that she was living beyond her abilities. Tessa did graduate late in 2008, but this was a hard fought victory that included a hospitalization for her emotional struggles. She emerged from this post secondary experience eager to begin the next transition into adulthood.

By late spring of 2009, another discovery came. Tessa was diagnosed with an anomalous coronary artery and congenital lung cyst. A second open heart surgery was proposed to mitigate a threat of a cardiac event. Several weeks of testing were needed to determine Tessa's unusual cardiac anatomy. During this time, Tessa struggled to speak. She turned to her "visual voice" for processing the feelings. Painting 8 to 10 hours a day, she produced a body of twenty oil canvases. During breaks from painting, we would walk along the lakefront where she would dissolve into tears, describing her waking nightmare fear. "What if they change one problem and it just creates another? Will I die trying to change my heart?" Ultimately, surgery didn't go forward, the risks for recovery out weighing the benefits. I felt both relieved and anxious about her future. Tessa's perception was that she knew this surgery should not be done. It was an acceptance of living within the questions and answers of VCFS/DiGeorge Syndrome.

Tessa set several goals for 2010. She focused on being a working artist. She has succeeded in getting her art work exhibited in several venues. She developed her skills in fashion construction and began showing her designs. Although she has complex cognitive learning disabilities, she has written a book she titled "Branches". It is about her journey of living within VCFS/DiGeorge, her constant travel companions. Tessa is living semi-independently in Milwaukee, not yet employed but actively pursuing being a working artist/designer. Every child comes with their gift to carry into their futures, no matter what their package labels may be. I remind myself often that TESSA spelled backwards reads ASSET.

As a parent I often saw that Tessa could withdraw into her art and not interact with others, so I realized that her talent was both a gift and a roadblock. Whatever we do as parents, it is important to remember that it takes many hands, hearts, and minds for children with special needs to find their true Self as they find their way in the world. For parents and siblings, it takes an incredible commitment of all that we are as families. There is so much to learn and so much to teach. I always told Tessa she needs to dedicate herself to understanding her health as well as her understanding her drive to do art. I saw that the two processes were similar and thought this could benefit her.

Postscript: By encouraging her daughter to express her fears and hopes through art, Tessa's talent became therapeutic. Art therapy, like music therapy and dance therapy are among known treatments for children and adults with emotional and psychological challenges and do not rely on direct communication like traditional counseling. For more information about art therapy and to find a credentialed art therapist please visit http://www.atcb.org/what_is_art_therapy/ Additional information about dance therapy can be found at <http://www.adta.org> or similar websites. One of several resources about music therapy can be found at <http://www.musictherapy.org>.

HOW I GOT MY SON TO STOP SUCKING HIS THUMB- THE LOW-BUDGET METHOD

By Sheila Kambin

My 6 year old son has been sucking his thumb from the time he had the coordination to get it up to his mouth as an infant. Like many other children with the 22q11.2 deletion, he has a prominent overbite. By the time he was 6, we had been told by multiple providers to try to get him to stop. The problem was that the behavior was intimately attached to his lovey. The lovey is affectionately known as "Lenny the Lamb." Lenny is a lamb head and a blanket from the neck down. My son has always used Lenny to self-soothe at bedtime. He would harmoniously suck his thumb while his little fingers kneaded Lenny's silk ribbon. After many attempts of breaching the conversation with my leery husband, I finally decided to try it when I saw him lose his first tooth. That scared me. The dentist told me that I better get him to stop before his permanent teeth grew in. Now I was on a mission.

As usual, my husband and I found ourselves split on the idea. He felt that it would be too traumatic to take his thumb from him. He worried that it would mean we would have to take Lenny too. After two years of conceding, I made up my mind to at least try. I went on line, prepared to spend close to \$100 on fancy thumb guards. I couldn't decide what to buy, got distracted and found myself at bedtime without a device. I opened up the drawer to my nightstand and pulled out a roll of paper medical tape. I wrapped his thumb from the base to the tip of the finger. I did this in a couple of layers. He looked at it. Fear immediately built up inside me. I thought to myself, Oh no, he's going to cry, he's going to get upset with me and take it off. Just then a playful grin appeared across his face, "Mommy look, now I have a thumb with special powers!" It's like a laser shooter." I smiled, and was instructed to wrap the other thumb. He ran around his room shooting at things for a while. After this, his younger sister requested a wrap for her index fingers so that she wouldn't pick her nose in the middle of the night. Next my son jumped out of bed, and excitedly ran down the hall to show his father how cool his thumbs looked.

I told my son that I want his teeth to always look this pretty and that the dentist told me that he must stop sucking his thumb. He went to bed and never once disrupted the tape. For approximately two weeks after this, the tape became less and less, until finally it was no longer needed. This was one of the easiest transitions I have faced with him. And Lenny remains, of course. What have I learned? Firstly, you do not have to spend money on expensive gadgets to accomplish cessation of thumb sucking. Second, and perhaps most important is that it was my husband and I who weren't ready to curb the behavior, not my son. Due to the obstacles he faces, all too often we have been guilty of over-protection and coddling. I am so pleased that this transition was so simple, I only wish I had tried it sooner!

(Editor's note: Sheila is a physician at Children's Hospital of Philadelphia and mother of her 6 year old son with VCFS.)

DO YOU FACEBOOK?



Over 1,500 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!

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 international scientific meetings every year, and publishing brochures, and offering a toll-free phone for questions, and a website with all kinds of information, 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!

FREQUENTLY ASKED QUESTIONS

Question: I have a question that I am not sure can be answered. Over the years I have heard from other parents and read on the Yahoo groups that young adults with VCFS who smoke pot could be at a greater risk of triggering or developing psychoses. Our son does not smoke pot but since I have read about this my husband and I feel we need to have a conversation with our son about it but we want to be informed with correct information before we do that. Is this theory correct? Do you know of any resources, articles, website links or any presentations that have been done on this subject? We have learned over the years to become as knowledgeable as possible about all aspects of VCFS, and this is one reason we attended annual meetings. This is just one more issue that we hope doesn't arise but we still need to be informed about it.

Reply by Dr. Robert Shprintzen: Your question is a complicated one. The average, or "typical" age of onset of psychiatric illness, specifically psychosis, often coincides with the time when kids are likely to be experimenting with illicit drugs. When two things happen together, it does not necessarily mean there is a cause and effect. That being said, illicit drugs have a profound effect on brain chemistry, and we know that this is a major risk for people with VCFS. The simple truth is that people in general should not be using psychotoxic or psychotropic substances for many reasons, ranging from legal to medically dangerous, and the more psychiatrically fragile they are, the higher the risk. Because people with VCFS tend to be more impulsive than other people, they are also at higher risk for preventing sound judgment from preventing the use of illicit drugs. The issue with adults with VCFS is tricky. Do you have legal guardianship over him at this time? Is he navigating in dangerous social circles? How tightly controlled is his environment? Even in adults with VCFS, the major factor in successful "life" management is largely related to controlling the environment as much as possible to limit exposure to potentially dangerous or confusing situations that would act as stressors, and those stressors would then increase the risk of mental disorganization and possible breakthrough of mental illness. We also need to keep in mind that we carefully examine the occurrences in the lives of people who have mental disorders looking for causes, but we do not necessarily examine the occurrences in the lives of people who do not. Because the majority of people with VCFS do not have severe mental illness, it may be importance for us to determine if there are specific triggers for the development of psychosis, and also if there are factors or environments that are protective.

MESSAGE FROM THE EXECUTIVE DIRECTOR



*Karen Golding-Kushner,
Ph.D.*

Dear Friends,

It is with great pleasure that I invite everyone to our 18th Annual International Scientific Meeting, to be held just a few months from now at the Hyatt Hotel in New Brunswick, New Jersey, USA. The scientific and educational part of the program is, as always, shaping up to surpass all of our previous meetings in scope and in the timely presentation of new developments. The abstract deadline has not yet passed and we are still receiving submissions, so the faculty list is not yet complete. For now, we can share that among our special guest speakers, new to the VCFS Educational Foundation, will be:

• Jack Levine, MD, a pediatrician and the Chairman of the NY State Chapter of the American Academy of Pediatrics' Committee on Developmental-Behavioral Pediatrics/Children with Disabilities from Brooklyn, NY, who will talk about "The Medical Home Model," a new relatively new approach to providing comprehensive primary medical care that supports and facilitates partnerships between individual patients, their personal physicians, and the patient's family.

- Tracy Vaillancourt, PhD, Associate Professor and Associate Chair in the Department of Psychology, Neuroscience and Behaviour at McMaster University in Ontario, Canada. She has published extensively on peer-relations and bullying.
- Greg Lof, PhD, Department Chair and Professor in the Department of Communication Sciences and Disorders, School of Health & Rehabilitation Sciences, MGH Institute of Health Professions in Boston, Massachusetts. He is widely recognized as an expert in Evidence-Based Practice in Communication Disorders.
- Michael Arvystas, DDS (Orthodontist, New Jersey) and George Cisneros, DDS, DMD (pediatric dentist and orthodontist, New York), both of whom have extensive experience with VCFS.

Of course, we look forward to hearing from returning international faculty that include Drs. Stephan Eliez and Bronwyn Glaser (Switzerland), Linda Campbell (Australia), Doron Gothelf and Merav Burg (Israel), Antonio Ysunza (Mexico), Robert Shprintzen, Sherard Tatum, Elliot Beaten, Alan Shanske, Donna Cutler-Landsman, Karen Ruckman-Lindsay,

Message from the Executive Director

(Continued from page 7)

Quinn Bradley, and others from the USA. Karen and Quinn and their spouses will be among the participants in a panel on VCFS and Marriage, and Karen will also be talking about Parenting and VCFS...when the parent is the one with VCFS. A preview is in this newsletter. It is a meeting you do not want to miss!

Do you want to attend the meeting for FREE? This year, we will include paid advertising in the Handout Book that is distributed at the meeting. We are asking everyone to solicit personal greetings or business greetings and advertisements to help raise much needed funds that will help pay for the meeting. We will waive the registration fee for anyone who submits \$500 in advertisements from any source. (Raising \$300 in ads will get a child's registration fee waived.) So it's that simple! Just send in your ads or greetings and the advertiser's payment, and you don't have to pay for registration. (Sorry, we have no control over the hotel room rate, it's a low as it can go – only \$99 per night.) This is a great deal, especially when you consider that your registration fee covers your breakfast (3 days), lunch (2 days), and snack/beverage breaks (5 in all), in addition to all of the programs at the meeting and the printed material!!!

Greetings and ads might be from friends, relatives, teachers, local business, hospitals, clinics, and so on, even your child's dance teacher or soccer coach. They might be wishing you well or advertising a business. Thanks to the Internet, businesses that used to be local are now global. Doctors, therapists, and hospitals are welcome to place ads and greetings, as are support groups. Place a greeting to thank someone who has done a lot for you or your child. Have someone who cares about your child to put a greeting in honor of him or her! Have a support group? Place an ad to attract new members. Be creative! Forms for soliciting ads and instructions for submitting the ads and payments are on our website, along with a form for [online registration](#) and a [hotel reservation link](#).

The meeting this summer will coincide with two milestones. One is a "big" birthday of our esteemed Founder and Past Executive Director, Bob Shprintzen. I will leave it to him to share his age, but let's just say we need to come out in large numbers to be sure he does not retire from the magnificent and important research and experience he contributes on a near-daily basis to our understanding of VCFS and effective treatment. The best present we can give him is to attend the meeting and thank him in person for way in which he has changed and continues to improve the lives of everyone reading this newsletter and millions more. (Note: You might consider putting a birthday wish to him in the Conference Handout Book, even if you are not able to attend the meeting! You can use one of the forms on the links provided above.)

The other milestone is that when the meeting ends, so will my eighth and final year as Executive Director of this wonderful organization. I know that the VCFSEF will continue to grow and to do the important work of bringing awareness and education about VCFS with the next ED at the helm. I will always be grateful for the support, but mostly for the friendship, you have all shown me.

See you in New Jersey!

Warmest regards,
Karen

– Karen J. Golding-Kushner, PhD
Executive Director

Bring the 21st Annual International Scientific Meeting of the VCFS Educational Foundation, Inc to YOUR hometown!

Proposals are being accepted for the meeting to be held in July 2014 and beyond. The meeting hosts chair the local arrangements committee, which is responsible for arranging the meeting site, social activities, childcare, and fundraising for the annual meeting, and work together with the scientific committee to create the scientific and educational program. For more information on what to include in your proposal, write info@vcfsef.org.

REGIONAL UPDATES



Latin America

Antonio Ysunza, M.D., regional director

From Chile, Mirta Palomares, Speech, Language Pathologist/Audiologist, and Gabriela Repetto, M.D. Clinical Genetics, report that the families from their support

Antonio Ysunza, MD, SciD
VCFSEF Regional
Director Latin America

group, and local professionals were extremely motivated to continue their work for the well-being of individuals with VCFS after a visit from Donna Cutler-Landsman, Scott Tatum, Antonio Ysunza and Cheryl Lozon. So far, there are over 300 families with one or more members with VCFS. The support group and professionals, who meet periodically, have worked hard to help families connect with each other, and receive appropriate information and guidance regarding treatment options. Research projects involving the families are conducted by the professionals. One such study is in the area of Genetics. The researchers are investigating the current status of people with VCFS with the hope of identifying local needs that can be addressed. There is also a website where general information concerning diagnosis and treatment of VCFS is available: www.svcfchile.cl. We invite you to visit and contribute.

At the hospital Gea Gonzalez in Mexico City, a protocol has just been completed to help identify patients with VCFS using video-nasopharyngoscopy. We hope to share these findings at our meeting in New Jersey this July.

Finally, we would like to thank the VCFSEF for the brochures in Spanish. These brochures have been a great aid for helping families to know what to expect, as well as provide reliable information for health and education professionals.



Europe

Bronwyn Glaser, Ph.D and Stephan Eliez, M.D., regional directors

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



Stephen Eliez, M.D.
Co-Regional Director,
Europe VCFSEF

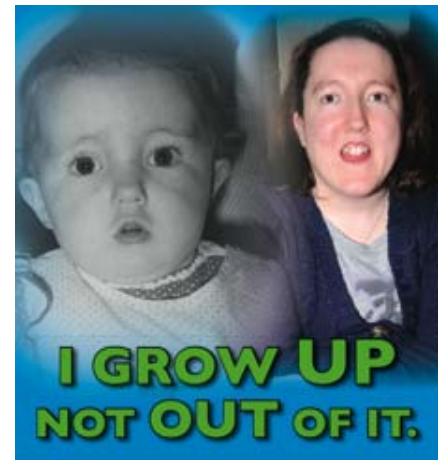
Greetings from across the Atlantic where Giulietta Cafiero writes to us that the Italian association, Aidel22, is busy planning their annual conference which will take place on the 26th of March. The title is "Research and clinical management: A unifying approach to the neuropsychiatric and behavioral features of deletion 22q11.2." The one-day conference will take place in Naples this year, where families can soak up some southern Italian sunshine. More details can be found at www.aidel22.it.

Frédérique De Clercq writes in from Generation22 in Paris. "2010 was a year full of interactions between families and health professionals all over France. 2011 is the year when we are preparing to celebrate Generation22's 15th anniversary! Yep, the foundation has existed for 15 years already, enduring so many challenges. Yesterday we were looking for families to create a stronger group and help to be heard. Today, the families and clinicians come to us, a sure sign of success. To celebrate Generation22, we are coming together in March 2012 for a weekend of presentations, workshops, and celebration! We are in the midst of making preparations and doing fundraising. In addition, the French government has renewed Rare Disease Plan for another 5 years. We are waiting to hear what it will mean for Generation22. We would like to direct interest toward research and keep the current treatment centers going strong. Treatment options for affected children are getting better, as are diagnostic rates. However, we need to direct more attention

toward taking care of adults who need it and improving psychiatric treatment, for which "old France" is undeniably obsolete."

Anne Lawlor writes to us from Ireland: "22q11 Ireland had a very productive parent/professional meeting with Prof Kieran Murphy and the research team on Sat 29th of January in Trinity College, it really is a substantial body of work that was undertaken - the data from the fMRI study is currently being analysed, early indications are that the results are quite promising. It was a programme given over entirely to the mental health issues relating to 22q, a difficult topic but one that needs raising and certainly needs further discussion. It was at this meeting that the group welcomed it's 87th family to join with us."

Coming across very strongly on the day was the significant fact that parents of the young adults/older children face a different set of challenges. This is perhaps illustrated by the poster which Anne has very kindly allowed me to use, it is her as a baby at about 9 months and now at 27.



www.22q11ireland.org
Registered Charity Number 0787 0787

Increasingly we are seeing the benefits of working more closely with our professionals in all aspects of managing VCFS/22q. The Europlan Conference, which took place in Farnleigh, was a hugely successful event following on from which Ireland gained a designated person Mr. John Devlin to help

Continued on page 10

Regional Updates

(Continued from page 9)

draw up and implement the Irish strategy for Rare Diseases. Kieran Murphy and I spoke on patient/ professional perspectives in the Empowering Patients workshop. Not only did this emphasize the benefits of working together, especially in relation to research, it also provided a marvelous opportunity to raise the public profile of our Irish 22q group. On Rare Disease Day itself, Feb 28th, our group was also involved with a very novel and entertaining way of discussing issues pertaining to rare disorders. The Global Health Forum in Trinity College devised the 'Play, Decide' game, which allowed for a very fruitful discussion to take place (http://www.grdo.ie/pdfs/Rare_disease_day_2011.pdf). Perhaps this also is a testament to the benefits of aligning our group with the umbrella Genetic and Rare Disorder Organisation (GRDO).

We are participating in no less than 3 research studies at the moment. The first is an assessment of the MH needs of our Irish 22q population, the 2nd is in conjunction with the DCC (Dublin Cleft Clinic) and the third will be on educational provisions and family needs of children with rare disorders (encompassing 22q11.2, Fragile X, Prader-Willi, and Williams Syndromes) we will keep you updated on these very exciting events, our fervent wish of course is that with a substantial body of evidence/research, the health and educational care-pathways (sadly under-supported at present) will improve drastically.

We are also meeting with some health-care professionals with a view to developing an information leaflet by parents as to what professionals need to know when their child is hospitalised. Looking forward to that one! This will involve some focus-group research (our parents will be researched out this year!) so perhaps as chairperson of the group I could take this opportunity to publicly extend my personal thanks and admiration to them all for their patience, perseverance and co-operation, they truly are a fantastic bunch.

More locally we are busy organizing our annual family conference due to take place on Sat 22nd Oct, some family day-outings and as always, fundraising

events, the first of which is the Ladies Dublin mini-marathon taking place on June 6th.

Social media sees our FB page being visited quite often and we are in the process of revamping our website. Internationally there seems to be a slow but steady growing connectivity between some young adults with the deletion. Personally I have made a great many connections with other mothers and sincerely hope that as many of them as possible will travel to Ireland for the VCFS conference in 2013, it will be surely wonderful to meet them all in person."

Those are a few of the things happening in Europe right now. We hope to see you all soon!



Linda Campbell, PhD
Regional Director,
Australia/New Zealand
VCFSEF

Australia/New Zealand

Linda Campbell, Ph.D., regional director

(Submitted by Maria Kamper, president of the VCFS and 22q11 Foundation: Making the Puzzle Easier)

News From Down Under

Australia will launch the first Worldwide Awareness Day 22q at the Zoo on the 22nd May. The day is set to see more than 40 locations and 13 countries joining together in an effort to raise awareness of VCFS/ 22q11.2 Deletion Syndrome, whilst enjoying a fun family day at the Zoo. As we are from Down Under we are the lucky country to be launching the day here in Sydney at Featherdale Wildlife Park in Doonside, NSW, on the day at 10am. This day has been put together by the 22q1 and You Center (CHOP) and the International 22q11.2 Deletion Syndrome Foundation. I urge everyone to participate it's not too late.

On February 28th the VCFS 22q11 Foundation held an event for World Rare Disease Day. The night saw Tim Maddren from Hi 5 (an Australian children's entertainment group), MC our event. The

night saw 60 people come together to celebrate the theme of the night "Rare But Equal". Earlier in the day Maria Kamper the President attended the World Rare Disease Day event at the Opera House with the Steve Waugh Foundation. Steve Waugh (Former Australian Cricket Captain and Australian of the Year) spoke of the need for a united plan for rare disease.

Recently in the VCFS 22q11 BlogSpot we posted an article, A Who is Who of 22q. This is an article to assist parents, families and those affected by VCFS understand the role of the different organisations and their roles. You can find read the blog at <http://www.vcfs22q11.blogspot.com> . We also have a fabulous parent who has become an Iron Man marathon participant to help raise money to send our families on a VCFS Camp. I am also excited to say that Louise Hall and Maria Kamper will once again be travelling to the USA for the international scientific conference. I hope to meet many of you in New Brunswick



Dianne Altuna
US/Canada Regional
Director

Us/Canada

Dianne Altuna, regional director

Dianne has been busy these last few months organizing, implementing and following up on all the Walks for Awareness that took place in North America and around the world this February. Please see her article in this newsletter.

CONFERENCE - AT-A-GLANCE

18th Annual International Scientific Meeting
The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.
 Hyatt Regency Hotel, New Brunswick, NJ, July 14-17, 2011

The following is a tentative outline for the program, including a listing of some of the speakers who will be presenting at the meeting. **This listing is very preliminary and subject to change.** We continue to receive submitted papers that will be added to this list shortly. **CHECK OUR WEBSITE AT WWW.VCFS.ORG FOR UPDATES.** CEUs will be available for Speech-Language Pathologists and Audiologists, Nurses and Nurse Practitioners, and CMEs for physicians.

Thursday, July 14

4:00 PM – 7:00 Registration
 7:00 PM – 9:00 Welcome Reception

Friday July 15, Saturday July 16, Sunday, July 17

7:30 AM Registration and Kids' Zone open
 7:30 – 9:00 AM Breakfast

Friday, July 15

8:00 – 9:00 AM Pre-meeting Primer Sessions (Select one)

- Introduction to Speech and language development and disorders
- Genetics and genomics for non-geneticists
- Introduction to Psychiatry, Cognition, and the Brain

Saturday, July 16 and Sunday, July, 17

8:00-9:00 AM Breakfast-with-the-Experts: varied topics in past included genetics, speech, education, medical care, dental and orthodontic issues, and more (sign up at registration table)

Friday July 15, Saturday July 16,

9:00 AM – 5:30 PM Seminars and contributed papers (see list below)

Lunch Hour Lunch-with-the-Experts: varied topics in past included genetics, speech, education, medical care, dental and orthodontic issues, and more (Sign up at registration table)

By appointment: BRIEF (10-15 min) private consultations with experts available (in speech, feeding and growth, education, behavior). Sign up at registration table only, first-come, first-served.

Friday, July 15

5:30 – 6:30 PM Annual membership meeting (everyone welcome but only members vote)

7:00 PM Annual Gala Dinner (Everyone welcome, separate fee)

Sunday July 17

9:00 AM – 1:00 PM Seminars and contributed papers (see list below)

1:00 PM Adjourn -See you next year in Canada!

Meeting Highlights and Topics including papers already submitted (abstracts still being received)

Keynote Address: How to determine if a therapy is based on science; Greg Lof, Massachusetts General Hospital Institute of Health Professions, Boston, MA

Research

Trends in research in VCFS: what has been learned and how has it helped?

Treatment trials in VCFS: what is the future?

Phenotype to phenotype correlations: the relationship of IQ to physical phenotypes in VCFS; *Nathaniel Miletta et al.*

Conference-At-A-Glance

(Continued from page 11)

The Genome and VCFS

When does a 22q11.2 deletion not cause VCFS? *Graf, Shprintzen, Lebel, Miller*

New directions in genome research; *Shashi, Kates, Goldstein, Shprintzen*

Heterozygosity of Tbx1 causes phenotypes in social behavior and spatial and working memory in mice; *Hiroi, Hiramoto*

Medical management

The Medical Home model; *guest speaker Jack Levine*

Scoliosis and its treatment

The prevalence of chromosome 22q11.2 deletions in 2,478 children with congenital cardiac malformation; *Agergaard, Olesen, Åstergaard, Christiansen, SÃ,rensen*

Dental and orthodontic disorders and treatments in VCFS

Speakers include *George Cisneros, DMD, DDS, and Michael Arvystas, DDS*

Speech and Language Disorders: therapeutic and surgical treatment in VCFS

Logic, theory and evidence against the use of nonspeech oral motor exercises; *Greg Lof*

Early intervention speech services: effective or not? (*Panel in formation, including Dennis Ruscello*)

Language skills in VCFS: assessment and intervention

Normal speech in VCFS: Achieving the Goal; *Golding-Kushner*

Velopharyngeal valving during speech in patients with velocardiofacial syndrome and patients with non-syndromic palatal clefts; *Antonio Ysunza, Ma. Carmen Pamplona*

What to do if VPI is detected early: surgery now or later?

Surgical Management of Hypernasal Speech in VCFS: results and complications from a series of Over 100 consecutive cases; *Sherard A. Tatum III*

Psychiatric and Cognitive Issues in VCFS

Anxiety and Its Management in VCFS

Self-Hypnosis to Reduce Anxiety in Patients with VCFS

Cognitive and learning issues in VCFS

Psychiatric issues and treatment in VCFS

How the deletion contributes to psychiatric issues in VCFS

A longitudinal study of the natural history of ADHD in VCFS; *Kevin Antshel, et al.*

Adults with VCFS

Marriage and VCFS: A panel of successful adults with VCFS and their spouses; *Quinn and Parri Bradlee, Karen and Doug Lindsay, and Kim and Derek Brown.*

Parenting and VCFS, when it's the parent with VCFS; *Karen Lindsay*

Education, school issues, and advocacy

Dealing with bullying and victimization; *guest speaker Tracy Vaillancourt, McMaster University, Hamilton, Ontario, Canada*

Education panel (*panel in formation, including Yolanda Ortiz, Donna Cutler-Landsman, Tony Simon*)

Focus on Math Interventions for Students with VCFS; *Landsman*

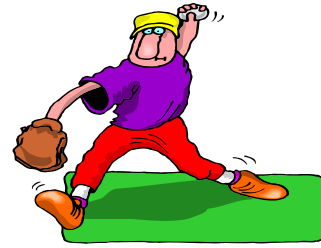
Texas Senate Bill 1612: Inception to Outcome; *Altuna*

The Importance of VCFS Support Groups; *Kamper*



**Sayreville Athletic Association
Adult Softball League**

PO Box 8
Parlin, NJ 08859
sayrevillesb@yahoo.com
732-553-0957



2011 Charity Softball Tournament

All proceeds benefit



Velo-Cardio Facial Syndrome Educational Foundation

Friday May 27, 2010 - Home Run Derby

Test your strength and ability to hit a softball.

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- Dinner for 2 at Texas Roadhouse
- Autographed picture from the Jets
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Saturday May 28, 2010 - Softball Tournament

3 game minimum with a bracket championship

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- Raffle Prizes

Home Run Derby -\$25 per person (\$25 re-buy in)
Softball Tournament - \$300 per team

For registration or sponsorship information please call 732-553-0957 or email sayrevillesb@yahoo.com
Visit our website at www.leaguelineup.com/sayrevillesb

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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 it's funding.



**18th Annual International Scientific Meeting
July 14-17, 2011
New Brunswick, New Jersey USA**

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For DISPLAY ADS & GREETINGS**

**This completed form AND camera-ready advertisement
AND full payment must be received NO LATER than
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Please enter my greeting in the handbook distributed at the 18th Annual International Scientific Meeting of the VCFS Educational Foundation, Inc., the proceeds of which will be used to support the meeting and to further the educational mission of the VCFSEF. The VCFS Educational Foundation is a 501(c)3 organization. Donations are tax-deductible to the full extent of the law.

Instructions: E-mail submission preferred. Email this form and ad (jpeg only, b&w only) to conference@vcfsef.org. Submit payment via PayPal (link from www.vcfsef.org). Form is not complete until you enter PayPal confirmation date and number in Section 3. If submission is made by regular mail: send completed form and camera-ready ad to VCFSEF Conference, PO Box 874, Milltown, NJ 08850. Enclose a check payable to the VCFS Educational Foundation, Inc. (US funds only) or PayPal confirmation information.

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**18th Annual International Scientific Meeting
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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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Please consider a donation to support our efforts:

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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.

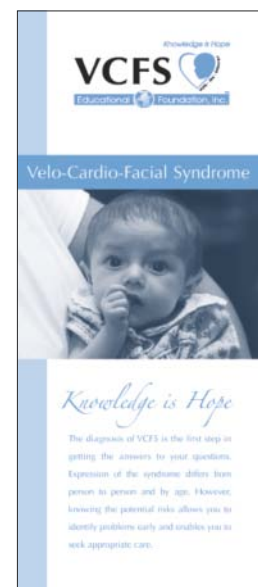


Knowledge is Hope brochure

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
- 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.

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