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Important News

Post Conference Connections

The VCFS Educational Foundation is offering two ways to access the information presented at the VCFSEF 17th Annual International Scientific Meeting in Salt Lake City, July 2010. Power point presentations/handouts and are uploaded to our website at www.vcfsef.org. There is also a link there to the audio recordings.

Save the Date!

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



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Welcome sign at Salt Lake City Airport

FROM THE EDITOR'S DESK



Sue Carneol, MS,
CCC-SLP

A "gathering" occurred in Salt Lake City this past July. Webster's Dictionary defines "gathering" as an *assembly; meeting, or a compilation; collection*. The VCFSEF 17th Annual Scientific Meeting from July 16-18 was all of that and more. It was an assembly of people of all ages, from around the world, who came to share and learn the most current information on Velo-cardio-facial Syndrome, while meeting new friends and compiling valuable resources. The planning committee, led by VCFSEF president, Steve Orton, worked tirelessly all year to make this "gathering" happen. A special "thank you" goes out to him and the entire planning committee: Robert Shprintzen, Karen Golding-Kushner, Alan Rope, Cristina Bush, Becky Moretti and their army of volunteers for a very successful and rewarding event.

In the first newsletter of this year, I wrote about how wonderfully "small" our VCFS community is; linking families and professionals through the help of technology. The miles again melted away this July weekend thanks to technology. When a last minute illness in the family prevented her from being with all of us in person, Karen Golding-Kushner was able to stay connected and chair productive EF meetings with the aid of Skype.

First VCFSEF Board meeting for the newly inducted officers and council members



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From the Editor's Desk

(Continued from page 1)

Our assembly consisted of over 250 individuals with VCFS, parents, siblings, extended family, physicians, government leaders, researchers, genetic counselors, psychologists, speech-language pathologists, social workers, nurses, and an army of teen and adult volunteers. Meetings took place on multiple levels: children and teens met others with similar experiences and interests. Parents met face to face after being "friends" on Facebook and professionals collaborated in person rather than in cyberspace.

The quality of presentations was outstanding beginning with a warm welcome from Utah's 14th Governor, Michael Leavitt. He served as Secretary of Health and Human Resources from 2005 to 2009 and as administrator of the Environmental Protection Agency from 2003 to 2005. We were privileged to hear Dr. John Opitz, speak. He is an international icon in the field of medical genetics who worked collaboratively with the late Dr. Angelo M. DiGeorge, another internationally renowned physician (for whom DiGeorge Sequence is named). Dr. Opitz is currently a Professor of Pediatrics, Pathology, Human Genetics, and Obstetrics and Gynecology at the University of Utah Health Sciences Center in Salt Lake City. Another special guest was Dr. Dennis Ruscello, Ph.D. speech-language pathologist from West Virginia University. Dr. Ruscello specializes in differential diagnosis of speech disorders related to oral motor and/or structural problems (i.e., palate anomalies) and he shared valuable diagnostic and therapeutic insights and suggestions.



Governor Michael Leavitt



Dr. John Opitz



Dr. Dennis Ruscello

I had the opportunity to meet and casually interview several attendees and volunteers throughout the weekend to get their impressions of the Gathering. Cassidee, a young woman with VCFS, shared her meeting with Dr. Alan Rope, geneticist and medical director of the Cardiovascular Genetics Clinic at Primary Children's Medical Center in Salt Lake City, who gave her suggestions on how to explain her syndrome to her employers. Cassidee said that she had been frustrated with other people always telling her what she could not do because she knew she could achieve more. He was very helpful to her.

Another mother said that she was relieved to know that she was "not crazy" about her concerns for her child and that many of the learning and medical issues were related to VCFS, "not just a cleft palate."

Justin, a 13 year old boy with VCFS, who has been to other meetings in the past, said that he always likes meeting other peers with the syndrome. This time he learned that being tired all the time was because of VCFS, not being lazy.

Many echoed similar thoughts about the opportunity to have their own questions addressed through face to face interactions with the professionals. The following comments were taken from the meeting's evaluation form that every participant was asked to complete at the end of the weekend.

- Very helpful to have families and medical professionals together. Having experts who are familiar with VCFS kids and conditions explain issues and treatment as well as dispel misconceptions
- The highlight was the adult VCFS panel. It overwhelmed me with emotion to see these happy/ high functioning individuals.
- Most rewarding part: Accessing resources for networking for optimal medical care.

Other's appreciated the opportunities to make new friendships.

- Bringing my daughter to meet and talk with other teens with VCFS was most rewarding.
- The most rewarding aspect of attending this conference was getting to meet with all of the families and colleagues in this field
- Knowing that there is really hope to see our children succeed and that there is a family to help us do and understand what we need to do.

Small breakout sessions for professionals and families



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From the Editor's Desk

(Continued from page 2)

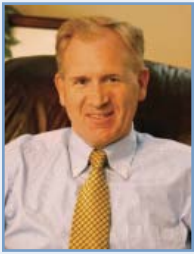
The annual meeting is the culmination of a VCFSEF presidential term. With appreciation, we bid “goodbye” to Steve Orton, whose leadership, wit and resourcefulness resulted in a very successful year for the Foundation. In this current era of “recycling,” we welcome back Julie Cooper as the new captain of our ship. As VCFSEF president 10 years ago, she returns with knowledge, experience, and passion. We have several other new officers and Council members that will continue to enhance the Foundation’s goals and mission. Please read on to meet these exceptional individuals.

Our motto is, “Knowledge is Hope.” With all we gained from our experience in Salt Lake City, there is a whole lot more hope for our children and friends with Velo-cardio-facial Syndrome. In our quest for more knowledge, please stay tuned for our next VCFSEF newsletter due out in January 2011. The theme will be “What’s in a Name?” or determining and defining accurate diagnoses in the field of VCFS. The deadline for the next newsletter will be December 1, 2010. I look forward to hearing from you.

- Sue Carneol, MS, CCC-SLP
VCFSEF Editor

PAST PRESIDENT’S PARTING PERSPECTIVE

My 2010 VCFSEF Conference Highlights



Steve Orton, Immediate
Past President of the
VCFSEF

I enjoyed meeting so many wonderful people at the conference in Salt Lake City in July. Here are a few of my highlights:

Governor Michael Levitt addressing the group.

The former Secretary of Health welcomed our group to Utah. He appreciated the parents, doctors and research scientists gathering to

better the VCFS world. I was happy to hear his stories of encouragement. His family was helpful with the conference. Two of his nieces gave 30 hours each of child care services.



parents attended the conference because they want the best for their children. Conference participation is an investment in improving the VCFS world.

Planning Committee: In addition to the volunteers for the conference, there were many on the committee that spent endless hours preparing for the conference. With the Executive Director, Dr. Karen J. Golding-Kushner providing direction the local committee made the conference happen with success.

Research: I am grateful for the research on VCFS that happened last decade because it has brought understanding and practical knowledge that helps my family today. There were many impressive projects presented at the conference. For parents, sometimes it’s difficult to recognize the value of the research work because the impact is not always immediate. It’s also difficult to understand the practices of quality research such as quantitative measures, focus groups, scales, predictions, analysis, control groups, blind and double-blind studies; let alone the complexities of the 22q11.2 deletion.

Professionals: I enjoyed seeing the professionals participate in the conference to learn and to share. They have taken the research and have found ways to apply their knowledge to improve the lives of those with VCFS. Surgical interventions, behavioral modifications, and educational strategies were discussed at the conference.



Volunteers in Action:

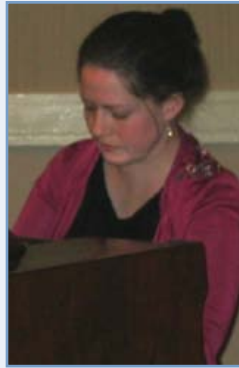
Over 588 hours of volunteer service were provided by family and friends. The volunteers worked hard to provide good experiences for those in the child care—the work was beyond babysitting, but was more

of workshop type of atmosphere for the children. I hope that parents gained more from the conference because of the volunteers who helped provide time and materials for the conference. A couple of weeks after the conference, several volunteers told me how they became attached with the children. They said that they missed seeing them. I believe

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Past President's Parting Perspective (Continued from page 3)

Talent Show: I was amazed and impressed by the willingness and the professionalism of those with VCFS who entertained us for the banquet. I love how these individuals have not leaned on limitations but have learned to succeed. What an example they are to all of us.



*Karen Ruckman-Lindsay,
pianist extraordinaire*

Friends: Hundreds gathered for the conference and I am grateful for the friends who care like me and want this to become a better world for those with VCFS and their families.



Thanks!

– Steve Orton (ortonio@digis.net)

Immediate Past President of the VCFSEF

MEET OUR NEW PRESIDENT: JULIE COOPER



*Julie Cooper,
VCFSEF President*

"The difference between a successful person and others is not a lack of strength, not a lack of knowledge, but rather in a lack of will." - (Vincent T. Lombardi)

Recognizing and respecting differences in others, and treating everyone like you want them to treat you, will help make our world a better place for everyone. Care... is your best. You don't have to be handicapped to be different. Everyone is different!" – (Kim Peek, inspiration for Rain Man)

Hello, I am Julie Cooper. I have been a nurse for 27 years. The first ten years of my career I worked in the happiest place on earth, the newborn nursery, as a mother baby nurse. I adored my job, but had to resign when my daughter, Katie, was born. I left while I was ahead, since I was too sleep deprived to provide safe care to others. Katie, now 18, has sleep apnea and didn't sleep through a single night until she was 7 ½ years old and she is still alive to talk about it.

Even though we saw many renowned specialists, Katie was not diagnosed with her congenital heart defect, from which she almost died of pneumonia, until she was three years old. I had concerns that Katie might have a syndrome, not knowing about VCFS at that time, and requested that the cardiologist test her for a genetic disorder. She was subsequently diagnosed with VCFS. Katie has numerous medical issues ranging from a submucosal cleft palate to hypoparathyroidism and hypothyroidism. Katie also has scoliosis and deformed feet. She wears hearing aids, glasses, orthotics and sleeps with a CPAP machine.

Being both a nurse and a mom to a child with VCFS gives me insight and a unique perspective and the ability to relate to both professionals and parents. The hardest job that I have had has been raising my daughter, Katie, and dealing with her multiple medical problems.

After Katie was diagnosed with the syndrome, fifteen years ago, I founded the Mid-Atlantic VCFS Support Group. At that time, and still today, I vowed that no one would fall through the cracks like Katie did. I transformed into a person whom was energized and passionate in my effort help enlighten and educate others about this condition. To this day, I am still president of the VCFS Mid-Atlantic Support Group.

I have a thirst for knowledge and information, which is why I find the conferences so beneficial. My goal is to make Katie Cooper the best that she can be. It is my philosophy that everyone has strengths and weaknesses and it is our job, as parents, to find ways to utilize their strengths and passions.

Together, by sharing ideas between parents and professionals, we can help our children live healthy and happy lives. When Katie is happy, which is now more often than not, her smile lights up the room and her joy is contagious. My daughter loves reading, animals (especially her horse and dogs), photography, and volunteering at animal shelters and horse rescue barns. She was accepted into 5 of the 6 four-year local colleges that she applied to last fall. She chose to attend McDaniel College, with accommodations, this year as a freshman. The college is far enough from home for her to have independence yet close enough to have her medical needs met.

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Meet Our New President: Julie Cooper

(Continued from page 4)

Many people have asked me why I would agree to volunteer twice to be president, as I was also past president of the educational foundation 10 years ago when we hosted the conference was in Baltimore, Maryland. "You must be the change you wish to see in the world" (Gandhi). Maybe it's because my husband considers me a glutton for punishment, but, in reality, I hope to make a difference. I have received lots of wonderful feedback, suggestions and support from many at the Salt Lake City conference. I do appreciate your input and, please, continue to feel free to contact me with your ideas. I will attempt to include as many ideas as possible in next year's New Jersey conference in order to keep it unique and ever improved.

This is your chance to pitch in and help. Please make your tax deductible donation to the Educational Foundation, or volunteer for the upcoming conference. You can specify your donation for specific areas of the conference such as handouts. Any donation would be greatly appreciated and we are happy to acknowledge it if you wish. Our membership is growing every day and, by attending the conference, you will have a great opportunity to meet new people and take home new information and ideas. Please join our crusade to enlighten families and caregivers, and work with professionals, thus resulting in the strongest knowledge base to help our kids lead the best life possible.

Top 20 reasons for families to attend the conference in New Brunswick, NJ July 14th-17th 2011.....

1. The Jersey Shore, New York and Philadelphia are nearby. Avis has a rental at the hotel so you have an excuse to go sightseeing
2. The hotel has a 24 hour complimentary gym
3. You can meet international people with cute accents
4. Learn from professionals about state of the art research before it is even published.
5. The hotel has a spa for massages, mani-pedis, and much more
6. We will serve cookies, and maybe even milk, if you behave
7. You can decorate cards for sick kids in the hospital and feel good about cheering up others
8. The hotel has an indoor pool and you can see who is brave enough to go for a dip
9. Tax free shopping for clothes.....YEAH!!!!!!!!!!!!!!
10. It is more fun than reading tabloid magazines while being stuck in the waiting room for hours
11. Your kids will make new friends while you meet new parents and network
12. You can get a drink at the bar located inside the hotel where they have 27 plasma televisions, so no worries about missing the big game.
13. You don't have to make your luxurious pillow topped mattress or bed for a few days
14. You will have a vacation from cooking.
15. You don't have to clean your bathroom while you are away

16. Wi-Fi high speed internet and iPod docking station in your room so you can party all night while playing your music, drinking from the mini bar, and chatting on Facebook
17. Coin operated laundry to clean your clothes up from the morning after
18. Coffee and newspaper in the room to wake up from the morning after
19. Because I am the mom and I said so.....that's why
20. And finally.....You won't hear Julie Cooper complain that you didn't attend

There is strength in numbers; exciting things happen when you put people with a common interest in the same room.

– Julie Cooper
VCFSEF President

DO YOU FACEBOOK?



Over 1,200 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!

Family, Friends, and Fans of the VCFSEF



Family, Friends, and Fans of the VCFSEF



RUNNING FOR AWARENESS

Support Ragan O'Malley's run in the New York City Marathon on November 7 to raise money for the VCFS Educational Foundation
By: Ragan O'Malley, mother of Grace



I have always loved the NYC marathon. Growing up in Brooklyn, the marathon route passed by my house. I would sit on my stoop cheering the runners as music from the movie Rocky blasted out of a neighbor's window. I still live in New York and the

marathon now passes a few blocks from my house. Every first Sunday of November (the traditional date of the marathon), I drag my kids out to watch it, whether we know someone running in it or not. First the elite runners pass; runners from all over the world race past us. Then come the runners in the wheelchairs or on the special bikes, pushing themselves along with their hands, or hand. The blind runners stream past, being led by volunteers from the Achilles Foundation. I cry every year, much to the embarrassment of my children. Eventually the masses of average runners pass by, some whipping along while others have more of a shuffling gait. Many of them wear their hearts on their sleeves. They are running for Italia, or for their sister who has breast cancer, or in memory of a friend, or simply because they want to be a part of this great event.

Like most of you, my life revolves to a large extent around VCFS. In my case, my middle child has VCFS. I can happily

say that she is doing well. She just started high school at a special education school and seems to be adjusting well. It hasn't always been smooth sailing, however, and just as we seem to get a handle on one problem another crops up. It is a familiar story for many of you, I'm sure. One thing I do know is that the VCFS Educational Foundation has been very supportive over the years; from hosting the conferences to providing informative materials for teachers and doctors.

I got the idea several years ago to run the NYC marathon and raise money for VCFS. In fact, I have entered the lottery for the marathon for 4 years in a row. However, like me, there are many who wish to enter and only approximately 37,000 are accepted. After 3 years of rejection, my entry was guaranteed. I am thrilled to be running the marathon this November 7th! I am not a fast runner, in fact, I am quite slow. I have also always been only a recreational runner, content with running 3 or 4 miles a few times a week. I have been training for months now, and I am confident I can do this (barring unforeseen circumstances). Although I am nervous, I am thrilled to have the opportunity to raise money for VCFS.

Please join me in my efforts!
Ragan O'Malley

(Editor's note: You can support Ragan and the VCFS Educational Foundation by logging on to www.vcfsef.org and clicking on the "Ragan's Run for Awareness" link)

CONFERENCE QUESTIONS AND ANSWERS

By: Karen Golding Kushner, VCFS EF Executive Director

You will read about the meeting we held in Salt Lake City throughout this issue of the Newsletter. I was terribly disappointed to have missed the meeting after so much planning, but appreciate everyone's understanding. Thanks to everyone who offered their support and concern. I look forward to seeing all of you at the NEXT meeting, which will be in my home state of New Jersey, USA.

There were so many positive comments about the content of the program, the organization of the meeting, and the networking and camaraderie among the participants, both professionals and families. The Panel discussion of adults with VCFS was extremely well received, and we are grateful to the special guests who joined us: Former Utah Governor Michael Leavitt, Renowned geneticist Dr. John Opitz, and international expert on speech issues associated with cleft palate, Dr Dennis Ruscello. Faculty and participants came from as far away as South Africa, Japan, Australia and other places in Europe, Asia, and the Middle East.

We appreciated the overwhelmingly positive comments on the post-conference evaluation forms. We also take seriously the occasional comments that are not so positive, the questions, and the suggestions. With the theme of "Conference" for this issue of the Newsletter, I am going to take the opportunity to answer some conference comments and questions.

Conference Questions and Answers

(Continued from page 8)

Question: Why don't you have separate sessions for professionals and parents?

Answer: The unique thing about the VCFS Educational Foundation is that the professionals and families are equal partners. Reflecting that philosophy, our meeting is unique in its format because of the vast opportunities for interaction and networking among all of the attendees. We provide the same information to everyone, realizing that the attendees are professionals in a variety of fields and parents who are intelligent, professionals in their own areas, and have done a lot of research on their own. They are entitled to every bit of information that is available, not just a "sanitized" or "dumbed-down" version. Professionals may be expert in their own area of interest, but have much to learn in the others. Parents and professionals not interested in certain topics are welcome to use the hotel facilities and skip anything not relevant to them.

We DO have some potentially separate sessions. We believe that if the information is important enough to be presented at a meeting, that parents and professionals should have equal access to the information.

However, recognizing that every person at the meeting has areas of more specific personal interest, we instituted the Break-fast-with-the-Expert and Lunch-with-the-Expert sessions. These enable participants to select the topics that most interest them and engage in a more intense and longer discussion with others who share that interest and with experts in that area. These sessions are extremely popular. They are specialty sessions, but are not segregated according to lay/professional, with a few exceptions. For example, last year we had a lunch session exclusively for people with VCFS. We had a session exclusively for parents of adults and teens with VCFS. We had a genetics roundtable intended for professionals (although parents were not excluded, it would not have been of interest to them). We welcome your suggestions for topics to include, and suggestions for experts who might be exceptional discussion leaders.

We always ask the Faculty to be aware that they are speaking to a mixed audience. It is not only mixed because there are clinicians and people who are not in medical fields, but it is also mixed because the faculty represent a wide variety of disciplines and they are not necessarily familiar with the jargon or vocabulary of the other fields. Some faculty are

accustomed to a mixed-discipline audience from meetings such as those of the American Cleft Palate-Craniofacial Association. This is new to others. Some speakers are more adept at speaking to a mixed audience than others, but they all try. We will continue to emphasize this point.

How we can help and what you can do?

While it is our intention to continue to have a single meeting for professionals, families, and adults with VCFS, we will be even more vigilant about making sure faculty know the audience is mixed. We will ask them to provide a list of ten key terms they are likely to use in their talks and provide us with definitions that we can include with the handouts. We will also reinstate the "Primer" sessions we used to hold. Those are early morning sessions held on Friday before the official meeting opens that enable attendees to gain familiarity with the concepts and We have done this for Speech Language Pathology, Molecular and Clinical Genetics, and Brain Imaging and Behavior. If you are not familiar with any of those fields, plan to be at the meeting by early Friday morning. If you think we should have a Primer Session in another area, please let me know ASAP.

Question: Why does the Faculty spend so much time on details like why they did a study or telling details about the results of their research? Why don't they just answer our questions?

Answer: They do answer questions, but only after they have presented the research that will back up their answers. The purpose of a scientific meeting is to present factual information about a subject. It is incumbent on a speaker to explain why their research was important and how they did it. It gives meaning to whatever they found out by doing the study. They tell the results and then explain what the results mean and why they are important. This is important for everyone to know, especially other professionals who may be doing similar or related research. Families should want to know that information, as well, because it explains the validity (relevance) of the research. In the early phases of research, the way in which results can be applied to treatment or clinical evaluation may not be clear. However, the underlying reason for any research is to lead to new understandings about VCFS and better ways to evaluate and treat any problems. Research presented at the annual international scientific meeting is at various stages of that process, so some faculty will be able to provide immediate and obvious relevance to treatment and some will not. All of the research is equally valuable. Without the preliminary stages, you cannot get to the later ones!

We DO leave time after each set of papers for questions from the audience. Faculty is also available during coffee breaks and throughout the weekend if there is not enough time for all of your questions. Most also include contact information in the presentations, and their affiliations are listed in the program. They will be happy to hear from you even after the meeting, if you have additional questions, or if you have new ones.

Conference Questions and Answers

(Continued from page 9)

Question: I really wanted to hear a certain paper but the time and day were changed and I wasn't told in advance. This was really disappointing. Can this be fixed?

Answer: The program is put together after an extended period of planning over several months. We typically have 17 or 18 versions of it before we publish it. (I would love for us to get to version 22 but it's never gone that far!!) The program, though, is subject to change without notice. This is always for reasons beyond the control of the Program Committee or Educational Foundation. These changes usually occur because of a change in schedule of a person on the faculty, resulting in a need to shift the time of one or more presentations. We know this is disappointing but it is beyond our control. This past year we had to make changes because a few faculty members had emergencies and could not come to the meeting at the last minute.

Solution: We will post changes in the registration area when we become aware of the need for the change, so anyone missing an announcement about the change can see it.

Question: I have some specific questions about my child/my patient and I need answers. Can I get help at the meeting?

Answer: We ask that people refrain from asking personal questions during the meeting or lunch sessions. Only general questions are appropriate or acceptable during those public sessions. Please keep in mind that the speakers do not know the child about whom you have a specific question, and the question time in the sessions are intended for questions that will be of interest to the entire audience.

What you can do: There are opportunities to sign up for private consultations with specialists, usually in speech and language, feeding, education, and behavior. These are 10-15 minute private meetings for parents and their child who want to have a quick opinion about a specific question related only to their child. Registration for these private consultations is available at the registration table on a first-come first-served basis. Professionals with questions about a particular patient may take advantage of these consultations, as well.

Question: Why didn't you provide a handout for each presentation at the last conference? Sometimes you provide a copy of the power point presentation, and sometimes it is just an abstract or summary.

Answer: It was our intention and desire to provide a complete set of handouts. At previous meetings, registrants received either a binder with the handouts inserted, or a spiral bound abstract book. Indeed, most (not all) speakers DID send us a handout, typically a version of their power point presentation. However, there was not enough funding to cover the cost of duplication and we were not successful in our attempts to get the printing donated. As a compromise, we printed copies of the abstract for each presentation. The presentations are now on our website and can be downloaded and printed. Some Faculty do not provide a handout.

How you can help: Make a donation to the EF to cover the cost of binders and duplication.

Question: I made a donation to support the meeting but did not get a thank you note. It took forever for you to post the presentations from the meeting. You are too slow to do things. Why should I continue to support the Foundation?

Answer: We make every effort to acknowledge all donations as quickly as possible. Sometimes there is a glitch in notification. For example, PayPal donations are supposed to generate a notice to our secretary and treasurer letting us know the details. Those emails are not always received. We are working on smoothing out that process.

What you can do: If you have made a donation and it was not properly acknowledged, please email secretary@vcfsef.org. This will help us in two ways. First, it will enable us to send a thank you note with details you may want to have for tax purposes and to send an acknowledgement to another party if your donation was in honor or in memory of someone. Second, it will alert us to a problem in our notifications so we can try to resolve it.

What else you can do: Please remember we are ALL volunteers, doing our best to keep up with a growing Foundation. When you call or email, please keep in mind that, like you, we volunteers have full-time jobs, families, household obligations, and other community involvements but are donating our time to the VCFS Educational Foundation. All of our volunteers are dedicated and sincerely want to help.

Conference Questions and Answers

(Continued from page 10)

Question: Why aren't all the presentations on the website?

Answer: We posted the presentations of all faculty from whom we had permission to do so. Some faculty provided an alternate hand-out so there may be something on the topic but not the entire presentation. Sometimes, faculty do not give us permission to post anything. This may be because the presentation included data that were not yet published and could not be shared on the web until they are in print, or because something in the paper HAD been published and posting it would have caused an infringement of copywrite. There are times that we do not know the reason that a speaker refrains from giving us consent to upload their talk, but must respect each faculty member's request.

What you can do: If there is a paper you are looking for, feel free to contact us or the author directly for more information.

Question: Why do you charge a registration fee for the meeting? Why is there a fee for children to attend? I think adults and children with VCFS should be able to attend for free.

Answer: The registration fee reflects the cost of food that is included: breakfast on three days, lunch on two days, and a snack/coffee break each morning and afternoon, for a total of five. The registration fee also has to cover part of the cost of printed material, audiovisual expenses (the hotels charge us to use screens, microphones, etc). We DO discount the cost for students in order to encourage them to attend – they are the future professionals and we want to nurture their interest in VCFS.

We could stop including meals in the cost of registration,

lower the registration cost, and give everyone time on their own for meals. However, that would mean eliminating the Breakfast- and Lunch-with-the-expert sessions because there would not be enough time to go purchase a meal and then go to the session. This is really a non-starter, as the feedback from the meeting indicates these sessions are among the most appreciated and popular sessions.

How you can help: Contact businesses, corporations, or individuals who may be able to sponsor a meal or a coffee break. We may be able to lower the registration fee if someone else pays the bill. If you know someone willing to make a donation like this, please let me know ASAP!

Question: Why isn't the dinner in a nice restaurant in the neighborhood? It would be nice to get out.

Answer: We have a minimum catering obligation that must be met in order to have use of the conference and meeting rooms without an additional charge. This saves the Educational Foundation thousands of dollars. To meet that obligation, we usually have to hold the dinner(s) at the hotel.

How you can help: Please make a donation to the EF to offset the cost of food and beverages, or to sponsor busses to take everyone off site for an evening activity AFTER dinner. Then, just sit back and enjoy the hospitality and convenience of dinner at the hotel.

Question: The Kids Zone staff should take the children outside and do more activities.

Answer: There seems to be a misunderstanding about the purpose and function of Kids Zone (KZ). KZ is not a camp or a day care center. It is a service we offer to enable parents to attend the scientific presentations without having children in the room. It is not appropriate to bring children in the sessions because they would be bored and it is unfair to expect them to sit quietly – they are children and should be allowed to act like children – run around, talk, and play. If they did that in the sessions, it would be disruptive to the other attendees and speakers. So, we have an option to leave them with supervisors. However, the supervisors are volunteers and often young college or even high school students. We cannot take the children on field trips or off the hotel property, or to the pool for insurance reasons. We ask that parents leave the children for no more than an hour at a time, then go visit with their children, take them out for a walk if the children need to get out, then bring them back and return to the

conference. We try to provide art supplies, games, TV and DVDs. The supervisors are not responsible for the children's meals. Parents are expected to be sure their children have the appropriate breakfast and lunch before taking their own meals. Supervisors also do not change diapers, provide medical care or treatment, or feed children.

How you can help: Please understand what Kids Zone is and is not intended to provide. Leave your children for no more than 60 to 90 minutes at a time... then take them out for a short break. Remember that you are responsible for making sure they have the appropriate breakfast and lunch, and for any diaper changes or other personal needs. Please remember to thank the volunteers who are giving up their weekend to watch your children. You can also help by making a donation to the EF to enable us to purchase art and other supplies that will help us keep the children occupied. Volunteer to organize a project or activity for the kids. Sponsor funding for a professional child-care provider (or two) to coordinate and supervise the volunteers.

Conference Questions and Answers

(Continued from page 11)

Question: I never thought about how much went into planning a conference. Why is it so expensive and how can I help for next year?

Answer: Here is a short list of some of the many expenses we need to cover:

- breakfast (x3)
- lunch (x2)
- snack/coffee breaks (x5)
- membership dinner
- welcome reception
- faculty dinner
- audiovisual equipment (screens, microphones, mixers, tech staff)
- duplication of handouts and other registration materials
- binders to hold handouts
- bags for binders and other registration materials – Donated by Cristina and Loren Bush
- faculty travel stipends (air, hotel, meals)
- crafts and supplies for Kids Zone
- supervisor for Kids Zone volunteers
- entertainment for Kids Zone
- continuing education credits for speech pathologists, nurses, doctors

- postage
- audio recording of proceedings
- entertainment for membership dinner
- printing of name badges
- decorations and goodies for membership dinner

Well, you get the idea- there are many expenses incurred in organizing a major international scientific meeting! If we meet our hotel obligation in filling a quota of hotel sleeping rooms and meet our obligation in catering costs (as noted above), we do not have to pay for the meeting rooms. That is a major savings of several thousand dollars.

How you can help: You can help by making a donation, by soliciting a donation from someone else (an individual or a business), or by organizing a fundraiser to cover one of these expenses. Also, take advantage of the excellent room rates we get from the hotels and stay there! You will help us meet our room quota and also will be able to take advantage of the informal interaction that always occurs in the lobby and other general relaxation areas of the hotel.

The most important way in which you can help is by helping us be sure EVERYONE knows about the 18th Annual Scientific Meeting on the VCFS Educational Foundation to be held July 14-17, 2011 at the beautiful Hyatt Hotel in New Brunswick, New Jersey USA and be sure to come!

Maybe those are some of the questions YOU have had. If you have others, feel free to write – together we can make each conference even better than the last!

See you in NJ next July!

Warm regards,
Karen

MEET THE VCFSEF LEADERSHIP TEAM

First meeting of the newly-elected Board
for 2010-2011 in SLC



OFFICERS



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

Dr. Karen Golding-Kushner is a speech-language pathologist who has specialized in speech disorders associated with cleft palate and related syndromes for over 30 years. She spent 17 years at the Center for Craniofacial Disorders at Montefiore Medical Center in the Bronx, New York that culminated in serving as Clinical Director of the Center, and is proud to have been one of the original Council members of the VCFSEF when it was founded in the early 90s. She also lived in Israel for three years, where she was Founder and Director of the Cleft Palate Team and the Department of Communication Disorders at Shaare Tzedek Medical Center, a large hospital in Jerusalem. She is currently in private practice in New Jersey. She says, "It has been a privilege to serve the Foundation as Executive Director since 2003, and I look forward to working with the new Board." You can reach her at kgkushner@vcfsef.org, execdirecto@vcfsef.org or 732-238-5494



**Julie Cooper, R.N.
President**

Please see Julie's story in her featured article in this newsletter. She can be reached at president@vcfsef.org



**Christina Bush
Secretary**

Cristina Bush is the mother of three boys. Her 6 year old, Landon, has VCFS. Cristina is proud to be a "stay at home" mom because it allows her to be involved in the many activities her boys do. She worked for many years as an Assistant Vice President for a community bank and went back to school in the field of Accounting. Cristina has lived her whole life in New Jersey, USA. She has been married for 13 years. Her hobbies include tennis, walking, reading and, most of all, being with her family. Cristina initially got involved with the VCFS Educational Foundation through Karen Golding-Kushner who was seeing Landon for speech therapy. Cristina first served as Membership Chair of the VCFSEF and is happy to now serve as the Secretary of the Foundation because "It just brings me closer to helping my son and all families that are affected by the syndrome." Cristina can be reached at secretary@vcfsef.org.

Officers

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Jennifer Stevens
Treasurer

She can be reached at treasurer@vcfsef.org



Susan Carneol, MS, CCC-SLP
Editor

Sue Carneol is a speech-language pathologist with over 30 years experience working with children with a variety of communication disorders. She has served on numerous multidisciplinary teams including the Velo-Cardio-Facial Syndrome (VCFS), Cleft Palate, Auditory Processing, and Cochlear Implant Teams at Children's Hospital of Wisconsin as well as IEP teams in the public school setting. In addition to her clinical experience, Sue has taught classes on Cleft Palate and Craniofacial anomalies at Marquette University and Counseling in Communication Disorders for the Department of Communication Sciences and Disorders program at the University of Wisconsin-Milwaukee. She has given numerous presentations on Velo-cardio-facial syndrome to speech-language pathologists, teachers and child psychologists throughout Wisconsin, and helped organize the VCFS Parent Network, a family support group that

provides educational and social events for children and their families in the Great Lakes area. Sue is currently in private practice in the Milwaukee area. She is very excited to be "on Board" with the VCFSEF and appreciates the opportunities her role as editor of the newsletter affords. She can be reached at editor@vcfsef.org

COUNCIL, LAY MEMBERS



Karen Ruckman Lindsay

Karen is currently living in Braintree, MA with her husband, Douglas Lindsay, and 1 1/2 yr. old daughter Alissa Grace Lindsay. She teaches private piano and violin lessons, from her home studio. She has been a proud member of the VCFSEF Board for one year and looks forward to the next two years. Karen was diagnosed with VCFS as a young adult. She can be reached at Ruckmankb@yahoo.com .

Council, Lay Members

(Continued from page 14)



Philippe DE CLERCQ

Philippe has been board member since 2007. He lives in Paris France and is the father of Astrid who was born in 1992 with VCFS. Philippe manages a translation company and helps the VCFSEF organize the translation of their international meetings in Europe. He can be reached at pdeclercq@wordshop.fr.



Ashli Chung

Ashli Cheung lives in Dallas with her husband Jeremy, and is the proud mother of two. Her oldest daughter, Ainsli, was diagnosed with VCFS at the age of three. Ainsli's late diagnosis helped answer so many questions, but also made the Cheungs aware of the incredible need to increase VCFS awareness. Ashli has been dedicated in helping the VCFS community and spreading awareness ever since. She is a founding member of VCFS Texas, and is proud to have worked with other members to help pass new legislation in Texas regarding VCFS. Ashli is excited with her role in the VCFS Educational Foundation, and is looking forward to another year of positive changes, new information and awareness for people and families affected by VCFS. Ashli can be reached at ashli@momerize.com.

COUNCIL, PROFESSIONAL MEMBERS



Wendy Kates, PhD

Dr. Wendy Kates is a Professor of Psychiatry, and Director of the Center for Psychiatric Neuroimaging at State University of New York Upstate Medical University. She trained as a clinical-developmental psychologist, and worked as a child psychologist for 12 years. After developing a hearing impairment that impeded her clinical work, she completed a post-doctoral fellowship that focused on brain imaging research. For the past 12 years, she has used neuropsychological testing and anatomic / functional magnetic resonance imaging (MRI) to study cognitive, emotional and brain development in children and adolescents with VCFS. Her current studies focus on 1) identifying risk factors for schizophrenia in youth with VCFS and 2) evaluating the effectiveness of a computer-based cognitive remediation program in adolescents with VCFS.



Merav Burg, Ph.D.

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

Williams syndrome. You are welcome to contact her at: 972-542456-110 or at meravbu@hotmail.com.

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Council, Professional Members

(Continued from page 15)

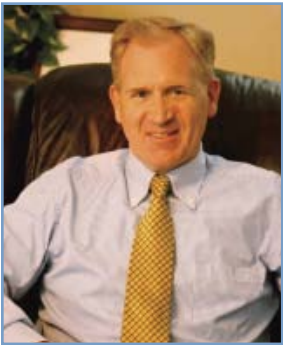


Virginia Dixon, Wood-M.A., CCC-SLP

Virginia "Ginny" Dixon-Wood grew up in rural southwest Ohio and received her BA degree in speech pathology and audiology from The Ohio State University. She went on for her master's degree at the University of Florida (UF) where she became involved with the Craniofacial Team in 1978 and has not left. Ginny has a joint appointment as a faculty member in the Department of Pediatrics and the Speech, Language and Hearing Sciences Department at UF. She is the Craniofacial Clinic Director and teaches an applied course in Craniofacial disorders and has developed a therapy program in CSD for teaching graduate students. She has had the opportunity to travel extensively with the UF Craniofacial Program to evaluate and treat children in Moscow and Kiev. She will be returning to Kiev in May 2011 to continue that program. She also has worked with the cleft palate team in Bauru, Brazil on feeding research.

Locally, Ginny has developed a residential speech camp program for children in Florida who have severe speech problems related to craniofacial anomalies. Ginny can be reached at woodgl@peds.ufl.edu.

EX –OFFICIO



Steve Orton, Past-President

Steve Orton and his wife are the proud parents of six children of which their youngest, Sterling, has VCFS. Sterling was born in 2002. He has had six surgeries and many early interventions that have helped him progress significantly. Steve works in the software industry for library systems. For the past twenty years he has traveled extensively though the United States and Canada as a trainer and sales consultant. Steve enjoys hiking the Utah mountains, playing pick-up basketball, savoring dark chocolate, growing veggies, and making homemade salsa. He and his wife are happy to be involved in the VCFS Educational Foundation. Steve can be contacted at ortonio@digis.net



Robert J. Shprintzen, Ph.D. Past-Executive Director

Dr. Robert Shprintzen (Bob) is currently Director of the Velo-Cardio-Facial Syndrome International Center and Professor of Otolaryngology and Pediatrics at Upstate Medical University in Syracuse, NY, USA. Together with about a dozen people, including our current Executive Director, Dr. Golding-Kushner, Dr. Shprintzen founded the VCFS Educational Foundation in 1993 and the first meetings of the organization were held in his office. Bob devotes nearly 100% of his time working on VCFS, which he described initially in 1978. His research activities cover many different aspects of the syndrome with a major focus on the causes and cures of the psychiatric and behavioral disorders caused by the deletion. He is currently Principal Investigator of a large clinical trial focusing on a promising medication for the treatment of psychosis in VCFS. He continues to focus on outcome studies for other aspects of the syndrome including

speech impairments, autoimmune disorders, growth and weight gain, and more. He has published many articles, chapters and books, more than 200, more than half of which focus on VCFS. He has assembled a team of more than 30 specialists who are focused on the diagnosis and treatment of VCFS. Away from work, Dr. Shprintzen enjoys nothing more than spending time with his family, including his bride of nearly 40 years (Debby) and his two grown children and their spouses, Jodi (and her husband Evan) and Adam (and his wife Rachel). The newest addition to family life is Debby and Bob's first grandchild, Isaac Matan Bloom, recently born to Jodi and Evan who conveniently live nearby. His other family consists of the hundreds if not thousands of friends he has made through the Educational Foundation, which remains so very close to his heart. Bob can be reached at shprintr@upstate.edu

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REGIONAL DIRECTORS



United States and Canada
Dianne M. Altuna, M.S., CCC-SLP

Dianne Altuna has over 30 years experience serving on cleft palate and craniofacial teams, currently at Fogelson Plastic Surgery Center, Childrens Medical Center, in Dallas. Dianne also lectures at School of Brain and Behavioral Sciences, University of Texas at Dallas. She was the founder of Camp C.A.R.E., a speech therapy camp for children with articulation and resonance errors. Currently, she is the Regional Director of the Velocardiofacial Syndrome Educational Foundation for the United States and Canada, she was involved in the passing of Senate Bill 1612 in Texas facilitating early identification of Velocardiofacial Syndrome. Dianne has presented at the local and national level. She has been a member of the American Cleft Palate Craniofacial Association since 1987. She can be reached at uscanada@vcfsef.org.



Continental Europe Co-Regional Director
Stephan Eliez, M.D.

Dr. Stephan Eliez is a child psychiatrist. He completed his studies at the School of Medicine, University of Geneva, where he also did his clinical training. He started his first research on VCFS in the early '90s. In order to develop his skills in the field of neurosciences, he first studied and became an Assistant Professor at Stanford University, California, from 1997 to 2001. Dr Eliez moved back to Geneva, Switzerland, in 2001, and started a Nationally Funded Research Program on VCFS. Over the years, he followed a longitudinal cohort of affected children and adolescents. In 2005 he became the Director of Child and Adolescent Psychiatry and the Director of Special Education for the State of Geneva. Dr Eliez is a member of the Education Foundation since 1999. He founded the Swiss Association Connect 22, of which he is

currently Vice President. He is a member of the scientific committee of the French Association Generation 22. He is currently the Co-Regional Director for Europe of the VCFSEF. In the last few years he has been creating a strong European network in order to promote knowledge and to help new national associations to build and develop throughout Europe. Dr. Eliez can be reached at +4122 388 67 41 or europe@vcfsef.org.



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

Bronwyn Glaser completed her Ph.D. work at the University of Geneva and currently does research devoted to understanding the effects of cognitive remediation on the developing brain in the context of VCFS and autism in Geneva, Switzerland. A native of the Napa Valley in California, Bronwyn's work has been enriched by the opportunity to work with VCFS families from other cultures. You can reach Bronwyn at bronwyn.glaser@medecine.unige.ch or Europe@vcfsef.org.



Australia and New Zealand
Linda Campbell, Ph.D.

Dr. Linda Campbell was born and raised in Stockholm, Sweden but went to London in the United Kingdom to study Psychology at the University College London and the Institute of Psychiatry. She started her research on VCFS as a PhD student in 2000 and is currently a post-doctoral research fellow at the Centre for Brain and Mental Health Research at the University of Newcastle in Australia. Dr Campbell is very interested in developmental psychopathology and is interested in following children with the syndrome from infancy to adulthood. She started doing her research on the relationship between brain, behavior, and cognition in children and adolescents with VCFS. Currently, there are a number of projects running in

her lab including a study looking for precursors of psychosis in young people with VCFS, the development of social cognition in children with VCFS, and the transition to adulthood in young people with the syndrome. She can be reached at linda.e.campbell@newcastle.edu.au

castle.edu.au or austrialia@vcfsef.org.

Regional Directors

(Continued from page 15)



Middle East Doron Gothelf, M.D.

Dr. Doron Gothelf was born and raised in Tel Aviv where he studied Medicine. He completed his residency in Adult and Child and Adolescent Psychiatry and research fellowship in Behavioral Neurogenetics and Neuroimaging at Stanford University. Dr. Gothelf has always been interested in the genetics and finding ways to improve the life of children and families facing chronic medical conditions. He has been treating and studying individuals with VCFS for 13 years. In 2001 he established the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel. Dr. Gothelf and the Behavioral Neurogenetics Center recently moved to Edmond and Lily Safra Children's Hospital at the Sheba Medical Center. The center is unique in that it combines a comprehensive clinical program with research. Besides VCFS, they

study and treat individuals with Williams syndrome, and fragile X syndrome. The center serves as a bridge to peace as it treats both Jewish and Arabic children. The focus of their research is to characterize the behavioral and psychiatric disorders in VCFS and to identify their genetic underpinning. They are also studying treatments for the psychiatric issues in VCFS. Dr. Gothelf has been an active member in the VCFS Educational Foundation since 2000. He can be contacted directly via email: gothelf@post.tau.ac.il or at middle_east@vcfsef.org.



Asia and Africa Nagato Natsume, DDS., Med.D.Sci, MD., PhD

Director, Cleft Lip and Palate Center
Aichi-Gakuin University Hospital
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Dr. Nagato Natsume can also be reached at asia_africa@vcfsef.org



Mexico and Latin America Antonio Ysunza, M. D., Sc. D.

Antonio "Tony" Ysunza is a physician at the Hospital Gea Gonzalez in Mexico City, a public hospital funded by the Government of Mexico, for patients with limited social and economical resources and no health coverage. He specializes in the diagnosis and treatment of velopharyngeal dysfunction and is a medical researcher in the area of craniofacial malformations. He has been on staff at the hospital for the past 25 years. Dr. Ysunza completed a medical residency in Audiology, Phonetics and Otoneurology in addition to a fellowship in Otolaryngology at the Albert Einstein College of Medicine in New York City with Dr. Robert Shprintzen at the time that Dr. Shprintzen's initial research on VCFS was published. Dr. Ysunza also holds Master of Science and Doctor of Science degrees on Neurophysiology, Audiology,

Language and Speech, from the National University of Mexico.

Dr. Ysunza has been the regional director for Latin America since 2003. It is his pleasure to answer questions or receive comments, from anyone in Latin America, in English or Spanish. He can be contacted at amysunza@cablevision.net.mx or latinamerica@vcfsef.org, or by phone at 52-555-652-7996

REGIONAL UPDATES

Australia & New Zealand

Linda Campbell, regional director

G'day Mates! We have had a fantastic winter Down-Under with lots of exciting activities. The VCFS & 22q11 Foundation has just finished the 2010 national VCFS Awareness week. The Awareness campaign started quietly at the end of July with a TV commercial aired on almost all free TV stations across Australia and on Foxtel. The commercial was played around 20 times a day and often on prime time, which means that a lot of people have now heard about VCFS (to see the commercial go to <http://www.vcfsfa.org.au>). The Awareness week was launched at the Children's Hospital in Westmead, Sydney with a full day of talks, discussions and great food. More than 70 people attended from all across Australia, with some participants flying all the way from Perth to attend. The highlight was a motivational talk from Sam Bailey, a man who despite being a quadriplegic has defied the odds to become a farmer, a pilot, a best selling author and a great inspirational speaker. There were a lot of teary eyes after his talk! During the Awareness week many campaigns around the country took place in shopping centres, schools and pre-schools especially on Friday the 28th of August which was the 'VCFS Pink & Blue day', on that day people were asked to wear pink & blue clothing for a gold coin donation. A number of 'Pink & Blue Day' coffee mornings were also held to increase awareness of the syndrome. In Queensland the VCFS clinic is progressing really well and they now have more than 100 families affiliated with the clinic. Some of the families also attend the family days arranged by the Queensland VCFS foundation.

Best wishes to you all,
Linda

Europe

Bronwyn Glaser and Stephan Eliez,
co-regional directors

Happy autumnus everyone! The long days of summer are dwindling over here in

Europe and our associations are back to their hard work.

Frédérique DeClercq, the president of Génération22, the French association, reports that Gen22 is continuing their visits to establish a list of reliable VCFS treatment centers all over France. Having covered the major cities, they are now visiting some of the smaller medical centers in less-populated areas where the association does not have representatives and where families are often most isolated (i.e., Tours, Nice Toulouse). These visits are helping nearby families to meet practitioners who can reliably help them. Gen22 has also been invited to join the « Collectif des Déficiences Mentales », a new network that allows associations to come together to join forces for common agenda items. In addition, France is seeing some exciting developments on the research front. One project is looking at the treatment of handicapped children in France, and Gen22 is in the process of finding 200 families (out of a total of 1000 families) who will make up a fifth of the cohort of this project. The project is funded by the department that allots money to handicapped individuals (MDPH) and is organized by Professor Verloes from the Robert Debré Hospital in Paris. Also, the Foundation Imagine (Institute of Genetic Diseases) is a new center that will be up and running by the end of 2012 in Paris. It is an enormous new center where one quarter of the space will be dedicated to treatment and three quarters to research. Patients will be in the center of the building with doctors' and researchers' offices arranged on the outside with the idea that everyone will feel more invested and collaborative with this arrangement. 120 researchers (24 teams) are already up and running. All current and future projects will be looking at the underlying mechanisms of genetic disease, improving care, and training students. Philippe DeClercq, VCFSEF council member, served as one of the French representatives at the Salt Lake City conference this year. He took detailed notes about each talk on the agenda and wrote an article for Gen22 families, transmitting some new developments in VCFS research and care to members who were not able to attend.

Giulietta Cafiero writes from Rome about Aldel22's "adult project." Aldel22 is collaborating with Policlinico Umberto I – Università La Sapienza di Roma to recruit and schedule adult individuals who would like to participate in an ongoing research study. Aldel22 is also hard at work helping their regional health care providers adapt a standardized diagnostic and treatment protocol for affected individuals. They are proud to have made VCFS one of the first "rare diseases" with a standardized treatment protocol in the "Campania" region. This is especially important in a socialized medical system to ensure that all individuals are able to access equitable care.

Anne Lawlor from Ireland lets us know what is happening on the Emerald Isle. She writes: *We had another wonderful conference back earlier in June with Donna Cutler-Landsman as the key speaker. Emphasis was very much on education and we realized very quickly how much we don't know and have yet to learn as parents and how our educators know even less! We introduced a Drama workshop for our young adults, which was very well received and we hope to do that on a regular basis at our conferences. Prof Kieran Murphy and I seem to be gaining a reputation as a double-act! Following on from our presentations at Rare Disease Day earlier this year we have been asked for a repeat performance at the upcoming conference hosted by the Genetic and Rare Disorder Organisation (GRDO) <http://www.grdo.ie/> on Fri 3rd Dec. focusing on patient empowerment. I look forward to the day when a person with 22q speaks at one of these events. Our FaceBook page <http://www.facebook.com/#!/pages/22Q11-Ireland/161363361613> is proving to be a huge hit and we are gathering supporters and possible visitors to our shores for 2013 as we host the 20th Annual International Scientific Meeting of the VCFS Educational Foundation conference. I know it is still almost 3 years away but I get so excited just thinking about it. Lots of hard work as you surely know but worth every minute of it. We are always pleased to welcome visitors to the page, just to say hi or leave a message; it's a great way to connect.*

Regional Updates

(Continued from page 19)

There is also a nice network of FB users amongst our young adults, which is great to see. We continue to network and build relationships both within the group and with other relevant organizations. Family days and fundraising events are high on our agenda. The ladies mini-marathon in Dublin raised in excess of 6,000 euros to add to our coffers and the first ever 22q Irish Golf classic takes place on Wednesday 15th September with our celebrity patron Ken Doherty joining in for the day. We are eagerly awaiting the completion of our educational psychologist's PhD, "Educational provision for and family needs of children with genetic syndromes". The update is that as soon as ethical approval is obtained the pilot questionnaire will be sent out and the PhD itself will hopefully be complete early next year. We envisage this as being a very valuable piece of research and one that will enable us to help change policy on the educational provisions for children in Ireland with genetic syndromes. 22q11 Ireland also moved into an 'office space' in Carmicheal House in the centre of Dublin <http://www.carmichaelcentre.ie/>. This has enabled us to make many links with other voluntary and charity groups and to learn and exchange valuable information. So, as you can see we are going from strength to strength, building capacity and making slow but steady progress. We hope for a website re-vamp soon and will keep you updated on our progress.

That's it for our European update this time!

Best,
Bronwyn and Stephan

Asia and Africa

Nagato Natsume, regional director

We established the VCFSEF Asia-Africa network office at the Speech, Hearing and Language Division of Aichi Gakuin University Hospital in January 2010. The International Cleft Lip and Palate Foundation (ICPF) has over 1,000 members including various NGOs, organizations and individuals from 56 different countries. The ICPF is a foundation composed of specialists

who are treating and caring for patients with cleft lip and palate. JCPF is a NGO authorized by The United Nations (UN). JCPF has a rich experience performing projects and missions in 20 countries across the world.

VCFSEF Asia & Africa network office was established in January 2010 and staffed by



Toko Hayakawa



Tomoko Tominago

We introduced VCFSEF through the JCPF News and Letter to specialists and lay members



The VCFSEF brochure was translated into Japanese and distributed to patients, oral and maxillofacial surgeons, plastic surgeons, speech therapists and other specialists who treat patients with VCFS and require brochures in Japanese. Brochures in Korean, English, Italian, French, Spanish were distributed to specialists from Africa and other areas at CLEFT 2010. We are proceeding with the VCFSEF Asia-Africa network website in Japanese.

- VCFSEF 17th was introduced to attendees at CLEFT 2010 ICPF (Seoul, Korea June, 2010)
- Over 300 participants from 40 countries attended to the conference.
- Information was e-mailed to ICPF members.

Latin America

Antonio Ysunza, regional director

Without a doubt, our most important regional news was the Latin American Symposium on Interdisciplinary Management of VCFS which took place on August 25-28 in Santiago de Chile. This conference was organized by the Fundación Chilena de niños con deleción 22q11.2 (Chilean foundation of children with 22q11.2 deletion). The foundation is supported by the Fundación Gantz (Gantz Foundation) and the Hospital Dr. Luis Calvo Mackena. These two institutions are also located in Santiago de Chile. The two-day conference was organized into two tracks: sessions for professionals and sessions for parents. Speech pathologists, psychologists, plastic surgeons, pediatricians, otolaryngologists from Bolivia, Peru, Argentina and several regions of Chile attended conference.

Two full-day clinics were held at the Gantz Foundation (a non-profit organization dedicated to the care of cleft palate patients), and at the Hospital Calvo Mackenna, the main children's hospital in Santiago de Chile. Many patients were evaluated during the clinics. Assessment of surgical outcomes and surgical treatment plans were completed by invited and local faculty. Educational recommendations and speech therapy programs were also outlined for patients and their parents.

I was impressed by the quality of the scientific presentations by our Chilean colleagues. During the parent sessions, many questions were addressed by the invited professionals. The families made sure we knew how much they appreciated our participation. It was a quite moving experience for all of us.



Donna Landsman, Antonio Ysunza, Scott Tatum

Regional Updates

(Continued from page 20)

A special "thank you" goes to the conference planning team which consisted of the president of the Foundation, Mrs. Patricia Jesam, mother of a handsome and smart boy with VCFS named Iñaky; her husband, Jose Miguel, the coordinator of the Foundation, Mrs. Mirta Palomares, a Speech and Language Pathologist, Dr. Gabriela Repetto, medical geneticists as well as many other collaborators. They all worked tirelessly for over a year to put on this successful event. Invited faculty included Dr. Scott Tatum, craniofacial surgeon from the Medical School of the Upstate University of New York in Syracuse, USA; Mrs. Donna Landsman, educational consultant, from Madison, Wisconsin, USA; Miss Cheryl Lozon, speech-language pathologist from Michigan, USA; and yours truly, the VCFSEF regional director for Latin America. Dr. Golding-Kushner could not attend because of a family obligation, and Dr. Robert Shprintzen could not attend because he has just become a grandfather. He did, however provide a video conference that was greatly appreciated. Everyone at the conference sent a sincere Mazel Tov to the new: Ta – Ta (affectionate term for Grandpa in Chile).

On behalf of all of the invited faculty, I want to express our sincere gratitude to the organizing committee for their invitation. We were made feel at home. Great wines (the best in the world), great food, (all invited professors are starting a diet after the conference), heartwarming experiences,

excellent scientific level. In sum, this was an extremely successful conference.

On another regional note, over 1000 Spanish VCFSEF brochure were distributed at this conference. Several more will be distributed in other regions of Chile, as well as in Bolivia, Peru and Argentina. Congratulations to everyone involved in the accomplishments of the Latin American region!



American faculty enjoying Chilean hospitality in El Mestizo-Chile

United States and Canada

Dianne Altuna, regional director

Diane has started contacting local VCFS support groups around the country. This is what she learned about a new group that just got up and running in Arizona.

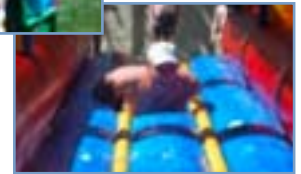
Jenny Rockrich, part of the AZ Family Support Group sponsored a BBQ in May at her home. Here is her story: "There is a core group of 4 moms that head up the support group. We meet the first Thursday of each month for coffee. Having a regularly scheduled meeting has worked

well for us as it gives us a chance to connect and there is always an upcoming meeting to invite new families to. From the time of our inception 3 years ago we have worked to create a network of healthcare providers and therapists with expertise in 22q. We assist families in navigating the AZ healthcare & education systems. We keep a database of families and help them connect with each other in various parts of the state. Once a year we all gather for a BBQ. "

Jenny Rockrich
www.vcf saz.org
602.908.7100



Arizona Fun



In August of this year, the VCFS Family Network in Wisconsin reports that 5 of their children with VCFS and their siblings participated in a one day camp experience sponsored by Children's Hospital of Wisconsin and Rainbow Camp in Fredonia, Wisconsin. Swimming, hayride, bonfire, singing goofy songs and making new friends were most memorable activities for the kids.

Please keep Dianne posted on all your VCFS/22Q11.2 Deletion events in your state by emailing her at us_canada@vcfsef.org.

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

VCFSEF DONATION FORM

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

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

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- Supports layout, printing, and distribution of informational brochures in multiple languages
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- Supports childcare and children's activities for children with VCFS and their siblings during the Annual International Scientific Meeting so that professionals with children and parents may attend sessions.

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

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VCFSEF MERCHANDISE & "KNOWLEDGE IS HOPE" BROCHURE

Knowledge Is Hope Bracelets

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

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

You can purchase your bracelets directly from the foundation's web site at http://www.vcfsef.org/products/product_list.php

For questions regarding wrist bands, contact wristbands@vcfsef.org.



Educational Foundation Logo Tee-Shirts

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

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

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

For questions regarding tee shirts, including shipping cost to other destinations, contact tshirts@vcfsef.org.

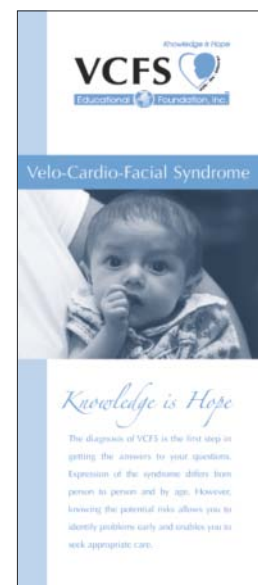


Knowledge is Hope brochure

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

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

- English
- French
- Italian
- Korean
- Spanish
- 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.

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