



VCFSEF NEWS

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Kelvin Ringold, Sr.

Editor
Design & Layout

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FROM THE EDITOR

It is a new year, for the Foundation at least, and this issue contains introductions to our current slate of board members and regional directors. We have all returned excited and motivated after a great conference in Plano, Texas and it was wonderful to meet so many of you there. As usual we have several updates in the current issue from around the world, including some exciting news from the Middle East. In this issue we also have another installment of our Global Forum, this time on issues relating finding quality medical care in your region.

Again I would like thank Kelvin Ringold for his help in assembling the final Newsletter and would like to thanks my "editorial team" Cheryl Dultz and Joel Johnson for their assistance with the Global Forum..

Tony J. Simon Ph.D.
Sacramento, CA

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Susan Marks, Diane Altuna, Dr. Karen Golding-Kushner, Dr. Antonio Ysunza and Dr. Robert Shprintzen address questions from attendees after a presentation, at the conference in Plano, TX in July 2007.

SAVE THE DATES !

15th International
Scientific Meeting

July 18-20, 2008
Troy (Detroit), Michigan
See details at
www.vcfsef.org

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FREQUENTLY ASKED QUESTIONS A PERSONAL CHALLENGE

Edited by: Robert Shprintzen, Ph.D.

This question was received a short while ago. It has been edited to leave out some personal information, but the basic premise of the question is not altered, and the answer is not edited. I would like to embellish on it a bit, however. One of the common issues facing people who have children with genetic disorders is guilt, and sometimes a defense against guilt is blame. These are very difficult feelings to deal with and to shake. There is always the nagging question, "if I had only done this, or if I hadn't done that." Although it may be very difficult to shake these feelings, in this case, the scientists who have studied VCFS have come up with answers that should allow parents to understand that it was nothing they did, that there was nothing they could do differently, and that the DNA rearrangement that happens to create the deletion is a part of a spontaneous process that happens constantly in the human genome. The large majority of cases of VCFS, over 90%, are brand new spontaneous mutations (meaning that neither parent is affected). In such cases, there is no fault, and there is no blame to be passed out in terms of how VCFS happens.

The question also points out another problem in interpreting the facts that we encounter frequently. The daughter of the writer was given the diagnosis of VCFS, and that daughter's child was given the diagnosis of DiGeorge. The continued application of multiple names to the same condition can be very confusing to patients, but it is no less a source of confusion for scientists. If you have any questions about the issue of names for the syndrome, read "The Name Game" that is on the VCFSEF web site.

Question: My child who is an adult was diagnosed with VCFS recently. She was exposed in utero to a number of toxic substances. I have done quite a bit of research and I believe with all of my heart that this toxic contamination is the reason for her deletion. She has a baby who was diagnosed with DiGeorge syndrome. Do you know if any of your members have been exposed to toxic chemicals?

Answer: The mechanism for the deletion that causes VCFS is well known and is related to an accidental rearrangement of DNA that occurs during meiotic cell division during the production of sperm cells or egg cells. Exposure to toxic substances or even mutagenic agents (substances that can cause DNA rearrangements) has never been implicated in VCFS. Because the deletion occurs in every cell in the body, it would be essentially impossible for an embryo at any stage to be exposed to a substance and cause the same deletion in each cell.

Answered by Robert Shprintzen, Ph.D

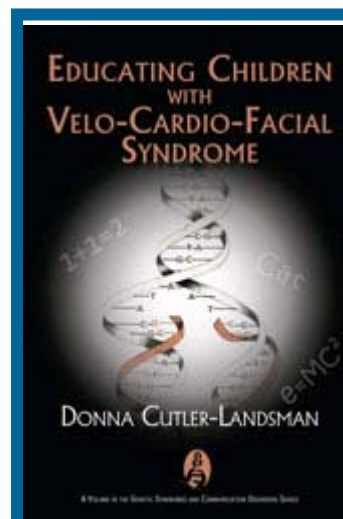
On Valentines Day 2006, my wife Brandy and I were blessed with twin girls Addison and Allison Smith. When the girls were about four months old we began to notice that Allison was not developing the same as Addi was. Our pediatrician sent us to Dr. Angela Scheuerle in Dallas and Dr. Scheuerle diagnosed Allison with VCFS. Through the VCFS Education Foundation website my wife and I were directed to a support group in Dallas that is led by Keri and Steve Alexander. It was during our first meeting that I learned the National Conference was going to be held in Dallas this year and on that day Keri challenged our group to raise \$10,000.00 for the conference.

Like many others that deal with VCFS, I want there to be a reason that Allison was born with this syndrome and for that to happen I felt like I needed to get involved with the Education Foundation not only to raise money for the foundation, I also want to raise awareness for VCFS in the East Texas area. And being an outdoorsman and a hunter I knew that if we were able to put a clay target shooting tournament together and get several others that like to hunt together we would be able to do both.

To put a tournament together I had to have about thirty volunteers and somewhere around fifty shooters. With a lot of help from the people at ABC Auto Parts, where I work we were able to have both. I had over thirty volunteers from ABC Auto and around sixty five people come to shoot at our event. We also had a lot of help from Whataburger of East Texas who donated drinks and over 100 hamburgers for the event and they even sent a team out to cook all of them for us. After the shooting was over and everyone was eating I got to explain what VCFS was to everyone and tell them of the conference and how the money we raised was going to help.

When we first starting planning this event, my goal was to raise \$5000.00 for the conference and I am very happy to say that we hit our goal. When all was said and done we raised \$5165.00 and more importantly, we got the chance to spread

(Continued on page 3)



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

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

FROM THE EXECUTIVE DIRECTOR

I did not expect to be writing again as Executive Director, but here I am. I am humbled by the confidence of the Nominating Committee and Board of Directors placed in me, and by their persistence and encouragement. They persuaded me to accept another four-year term of office. I will continue to do my best to serve this wonderful organization.

In this issue of the newsletter, you will read about our recent scientific meeting, held in Plano, Texas. The presentations were significant and of excellent quality. Many speakers presented clinical data not yet even published, a reflection of the importance of our annual conference as a forum for sharing the latest information. Speakers and attendees came from around the world to be part of the meeting. Most of the handouts and presentations will be available on our website very soon. MP3 and audio CD recordings are also available for purchase directly from Conference Copy. Look for an order form in this newsletter.

It is with great pleasure that I introduce our new Board members, Jennifer Lewandowski, (President), Jennifer Stevens and Philippe DE CLERCQ (Council: Lay), and Merav Berg (Council: Professional). We also welcome co-Regional Directors for the United States and Canada, Donna Landsman and Dianne Altuna. We thank Lisa Jennings, who served on the board as Treasurer for 11 years and has now assumed the position of Chair of Membership. We also thank Keri Alexander, now Past-President, and our other outgoing board member, Doron Gothelf, who will continue to serve in his capacity as Regional Director for the Middle East. Our appreciation also to Dominique Pfeiffer, who served as local chair of the 2006 meeting in Strasbourg and stepped down from the Board with one year left to her term for personal reasons. We wish her well, and thank Philippe for agreeing to finish the remaining year of Dominique's term. Read about each of the Board members and Regional Directors in a separate article.

All members of the Foundation will receive two copies of our new brochure, VCFS: Knowledge is Hope[®] in the mail very soon. Please keep one for yourself and give one to someone who will benefit- the parents of a child you treat, a doctor or therapist treating your child, a teacher, a neighbor. We are enlisting the help of all of our members- professional and lay- to help us in our mission to increase awareness of VCFS and to disseminate educational information. More brochures are available on request via our website, and packs of 25 brochures will ship with a display box. If you are not on our mailing list (which is a different list than the email list), you can join by filling out a membership form, also available online. Non-members can also request copies of the brochure, but we do hope those interested will join and help support the activities of the Foundation through dues or donations or both. Thank you in advance for your continued support.

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

A PERSONAL CHALLENGE...

(Continued from page 2)

the awareness of VCFS by telling others what it is and how it affects so many families.

Now that the shooting event and the Dallas conference are both over I don't want our efforts to end. My family, friends and the company I work for still plan on raising money for the education foundation. Some events we have come up with to raise money are to have a silent auction with prizes donated by ABC Auto Parts at our next customer appreciation event and several of my friends are planning to have a charity Texas Hold'Em poker event that will have a \$20.00 minimum to play and all of the money we raise at both events will go to the VCFS Education Foundation.

In conclusion, I would like to challenge each of you to do anything you can to help raise money for our foundation and to raise awareness in your area. For me not only has it helped the foundation by raising money, it has also helped me in dealing with the question that all of us have asked ourselves at one time or another. The question Why us, why was my family affected with this syndrome? I think by getting involved with the education foundation and with your community you will find the answer.

Sincerely,
Justin, Brandy, Carter, Addison and Allison Smith

EDUCATION OPPORTUNITY

Distance Learning Webcasts
*from the University of Wisconsin
Madison Extension Office*

**Educational Interventions for
Students with
Velo Cardio Facial Syndrome
(22q11 deletion syndrome)**

Learn about this important new genetic
deletion syndrome!

For more information and schedule
of upcoming webcasts, go to:

<http://www.vcfsef.org/events/webcast.htm>

WORDS FROM THE PRESIDENT

Hello to everyone from the Motor City-Detroit, Michigan! I, along with the VCFS Support Group of Michigan, are ecstatic about having the opportunity to bring the 2008 Conference to our area.

I am honored to be the President of the Foundation this year and look forward to coordinating the conference. I have a wonderful family. My husband, Michael and I have been married for 13 years and have 3 beautiful children. Katie is 9 years old and has VCFS, Sara is 6, and Jack is 3 years old. Needless to say, we have our hands full but enjoy the three precious lives we have been given.

Katie was 4 years old when she was diagnosed. My first indication was when she was three. I took her for her regular check-up and said to the pediatrician, "She sounds mumbly to me". The doctor looked in her mouth and suspected a submucous cleft due to her bifid uvula. We started speech therapy and soon after noticed that her knee was very lax and was prone to dislocating. Katie ended up spraining her ankle due to the dislocation and upon seeing the "Head" pediatrician, he said "I wonder if there is a correlation between her hypermobility and speech. He wasn't going on much but referred us to the Chief of Genetics at our hospital nearby. The geneticist threw out a few syndromes it could be but wasn't really suspecting anything. He drew blood for normal DNA screening and also ran a FISH test. Well, lo and behold they called me with the diagnosis of VCFS. When I look back at some minor signs, much of the picture comes together. We struggled to breastfeed her, but she did it, very successfully! Katie achieved her developmental milestones but just on the borderline of all the norms. We always noticed her hypermobility, she has chronic constipation, wears a brace on her knee for gym and other active sports, has numerous outside allergies, and struggles in math. Katie is going into 4th grade and is such a hard worker. She receives services for math and speech and the social worker sees her 2 times a week. Katie is very easy going and really has a zest for life! We are proud of all the

*Without the dedication of these people,
I can't imagine where our children would be
and how our lives as parents would be,
dealing with VCFS.*

achievements she has made so far. Although learning doesn't come easily for her, Katie puts her best efforts forward!

Our local support group consists of 11 families. I can attest to the fact that we feel like family. Without this core group of families, I could not imagine what life would be like dealing with VCFS. I feel blessed to have all of them in my life. For this reason, we are so motivated to move forward and plan this conference. Our wheels have been spinning after watching Keri and her support group put on such a beautiful conference in Texas. We can attest to bringing you a conference that mimics the 2007 conference. The latest and greatest information and research will be presented along with a well organized "Kids Zone", so parents need not worry about their children, as they absorb the contents of the conference. We will hold the conference in Troy, Michigan. This is about 20 miles north of the city of Detroit and about 35 minutes from the airport. We have numerous nearby attractions, malls and restaurants, and the northern part of the state is incredible this time of year. Please come and see what the Motor City is all about. The conference will take place July 18-20, 2008-Save the date!!!! The following website can entice you to come visit www.visitdetroit.com.

Finally, I have such passion for this Foundation and the members/professionals involved. Without the dedication of these people, I can't imagine where our children would be and how our lives as parents would be, dealing with VCFS. I am happy to dedicate my time and efforts to the upcoming year and bring us to, yet another, enlightening and successful conference.

Thank you!!

I look forward to meeting many of you in 2008.

Jennifer Lewandowski

REGIONAL UPDATES

Regional Update from Latin America

There have been some interesting developments in the last few weeks. I was invited to a scientific meeting in Santiago de Chile. Before this meeting I had the opportunity to travel to Buenos Aires. Up there I met with about ten families from the local VCFS support group: Asociación Civil 22q11. One member of this group is a mother of a 28 year old lady affected by VCFS. This young woman has been struggling with the disease for so long. At this point in time she is eager to get in touch with other adults with VCFS. I told her she could

write a letter relating her experience, I would translate it and send it to be considered for its inclusion in the section "Rays of hope" of the Foundation's Newsletter. In this communication she would include her e mail address so she could be contacted by other young people affected by VCFS.

The enthusiasm of the Argentinian group is encouraging. They are quite well organized, they keep communication with families all over Argentina, including the cities of Mendoza, Euquen, Bahia Blanca, among others. The meeting was held quite casually at a restaurant with a play ground for

REGIONAL UPDATES ...

kids, every family presented questions, my experience was quite similar to the meeting we had in Dallas, especially during the breakfast sessions, only the meeting in Argentina was in Spanish of course. The next day I met with a group of speech pathologists who are treating VCFS patients, I spent quite a few hours with them discussing diagnosis and treatment of speech and resonance disorders related with VCFS. After Buenos Aires, I went to the meeting in Chile, the meeting was organized by one of the most important Children's Hospitals of Santiago. Over there, surprisingly enough, I found another well organized support group, their president is Patricia, a mother of a girl affected by VCFS. She is full of ideas and energy, actually, she showed me a copy of a letter she sent to our executive director presenting the group. The group in Chile has a good relationship with several professionals interested in VCFS. I mentioned that the site for the 2010 meeting has not been decided yet. If the idea to hold the meeting outside the US is still on, the group from Chile would be highly interested in presenting a bid for this meeting.

In summary, it was a great experience to meet with these groups of families, it is interesting that despite the obvious cultural and Language differences, the families from Latinamerica are quite similar to the families I have had the opportunity to meet with in the US or in Strasbourg. The reason for this similarity seems simple, they are all united by one common goal, the well being of their children affected by VCFS. Finally, when I came back from this long trip, in my office I met a 9 nine year old beautiful girl from Brasil. She was diagnosed a few years ago and now her family moved to Mexico City. This girl has been treated by a speech pathologist with a great interest in VCFS. She knows quite a few patients affected by VCFS, and she sent me a letter in which she explains that some families from Sao Paulo are interested in starting a support group.

By the way, I was told that all these families from Southamerica send a warm "saludo" to all their friends in the foundation. They hope they can meet with you personally in the near future.

Saludos a todos.....Antonio Ysunza. Mexico City

Regional Update from Europe

"Bonjour", "Grüezi" and "Ciao" from Switzerland, the headquarters of the VCFS-EF European Network! We are happy to report that the new academic year has put in motion many conferences hosted by national associations in Europe. *Connect22* in French Switzerland is planning their annual VCFS Day for October 13th, *Generation22* of France is looking ahead to December 1st, and Isabelle Vanlathem of *Relais22* in Belgium reports that plans are already underway for a Belgian symposium April 26, 2008! One of the goals of the network is for each member association to host at least one informational day every year. The one-day conferences generally bring expert professionals to the area to speak with parents and families about pertinent issues relating to topics such as education, medical care, psychiatry, speech issues. Parents have given very positive feedback about these sessions and despite the ease of telephone and internet resources, the chance to meet

face-to-face has been effective at building some of the newer associations and spreading information about VCFS!

Isabelle also reports progress toward another of the network's major objectives, "We are putting energy into lobbying for recognition of the syndrome from the medical authorities here in Belgium." Obtaining recognition would be an important step for Belgium, as well as for other European organizations wishing to follow suit. Contact information for the relatively new *Relais22* was recently added to the VCFSEF website, and those who wish to get in touch with Isabelle and colleagues can send an email to: info@relais22.be.

Finally, Giulietta Cafiero of *Associazione Italiana Delezione Cromosoma 22* writes that she is busy working on fundraising for a 2009 conference in Rome. She has a series of meetings set up in September and hopes to have some good news for the European Board meeting in October.

For those of us "Europeans" who participated in the Plano, Texas conference in July, we would like to congratulate all of the families and professionals who made the conference such a tremendous success and a wonderful example for other groups to follow!

Bronwyn Glaser, Geneva Switzerland

Regional Update from the Middle East

Summer has been exciting and busy. We are so jaded in the Middle East by constant reports about suicide terrorists, missile and rockets landing in Sderot or curfews imposed on the West Bank that we lose sight of positive endeavors coming from the region.

This summer VCFS served as a bridge to peace between Israel and our Jordanian neighbors. Dr. Robert Shprintzen came to Israel as a guest of our Behavioral Neurogenetics Center. He was enthusiastically welcomed by the patients, parents and professionals. During his five-day visit he lectured in six different forums including our annual Families Day, a congress on VCFS for professionals, and the grand round meeting of Schneider Children's Medical Center.

One of my missions as the Middle East Regional Director of the VCFS International Foundation is to spread the word of VCFS to our Arab neighbors. About 20% of the 150 individuals with VCFS treated in our clinic in Israel are Arabs. We have recently joined forces with the Canada International Scientific Exchange Program (CISEPO), which has been establishing partnerships between Israelis and Jordanian in the fields of medicine, research, education and training. With the support of CISEPO, Dr. Shprintzen and a small group of Israeli physicians visited King Abdullah University Hospital and the annexed Princess Haya Biotechnology Center at Jordan University of Science and Technology in Irbid, located at the North of Jordan. We met with the directors of the hospital, and senior staff of the biotechnology laboratory and neuroscience program. The hospitality we received was outstanding and our hosts were very welcoming and friendly.

(Continued on page 6)

REGIONAL UPDATES...

(Continued from page 5)



Dr. Shprintzen lectured to the university audience about VCFS and the Jordanians were especially appreciative of his visit and the knowledge he shared. Currently VCFS and other microdeletion syndromes are not diagnosed in Irbid. However, the hospital and laboratory in Irbid are developing rapidly and with training of molecular scientists and clinicians, establishing screening for VCFS in Jordan is feasible.

Continuing discussions between Dr. Shprintzen, CISPEO leaders, Israelis' and Jordanians' scientists are being held to make the necessary steps for establishing such a VCFS screening program in Irbid.

Doron Gothelf, Tel Aviv, Israel

SPECIAL THANKS

The VCFSEF sends special thanks to these generous Inaugural VCFSEF Brochure contributors:

Kevin Greek
Design and layout

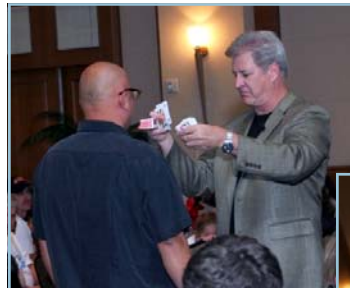
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The VCFSEF sends special thanks to these generous 14th Annual International Meeting sponsors and donors:

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David Magee Magician
Hawaiian Falls and the "Veggie Tales"
Dallas Rough Riders
North Dallas Florists
City of Plano
Big Lots
National Charity League of Richardson, UTD
Graduate Students
UNT Graduate Students

CONFERENCE PICS



Left, magic and mind reading; bottom, fun for the kids at the Friday night dinner in Plano.



Left, a trainer from the Dallas Zoo amazed the children with exotic animals.

Below: After these therapy dogs performed and made friends in the Kid's Zone, they posed for this "family portrait"



BOARD OF DIRECTORS



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

Karen Golding-Kushner is a speech-language pathologist and have specialized in speech disorders associated with cleft palate and related syndromes for 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. 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 is proud to have been one of the original Council members of the VCFSEF when it was founded in the early 90s. "It has been a privilege to serve the Foundation as Executive Director since 2003," and she looks forward to working with the new Board as she enters her second term in office. You can reach her at kgkushner@vcfsef.org or 732-238-8803.



Jennifer Landowski, President

I am married to Michael and I have 3 children, 9 yr old Katie, 6 yr old Sara, and 3 yr old Jack. Katie has VCFS but her life is not dictated by the syndrome. I have been a stay at home mom for the past 9 years, but have a degree in Elementary Education with Early Childhood Development. I am very active as a volunteer for the children's school, our church and the local hospital. I am very honored to be part of the Foundation. Our local support group and I are excited to host the 2008 conference and to promote local awareness of VCFS. I look forward to seeing everyone again and meeting many new faces. Please feel free to contact me at jlew@wowway.com.



Jeff Landsman, Treasurer

I am married to Donna, and we have two adult children (ages 26 and 23). Michael, our 23 year old, was diagnosed with VCFS when he was 7 years old, and Donna and I have been active with the VCFS Educational Foundation since that time. I am an attorney practicing law in Madison, Wisconsin. My email address is jlandsman@wheelerlaw.com.



Carrie Heran, Secretary

Our beautiful 16-year-old daughter was diagnosed with VCFS/22q deletion when she was almost three years old, and my husband and I have been members of the VCFS Educational Foundation since 1995. We live in Northern California, and we welcome families to contact us any time. You can reach me by phone at 916-624-1711, via Skype at carrie.heran, or by email at vcfsparent@aol.com.



Tony J. Simon Ph.D., Editor

Tony Simon is a pediatric cognitive neuroscientist, which means that he studies the relationship between the "hardware" of the brain and the "software" of the mind as they change during childhood. His research focuses on explaining and eventually remediating cognitive impairments seen in genetic conditions that can produce mental retardation, developmental disability or psychiatric disorders. His main interest is in children with deletions of chromosome 22q11.2 or VCFS. A native of London, England Tony moved to the US in 1988 and now lives very happily with his wife, Virginia (Ginger) and young son, Benjamin in Northern California. Tony's interest in children with VCFS came about almost by accident because of his earlier work on how the human brain comes to represent and process numbers. He is thrilled to be working on this exciting project with these wonderful children and their families and finds his current work to be the most fulfilling thing he can imagine doing. Tony is currently an Associate Professor in Psychiatry at the University of California, Davis where he works at the M.I.N.D. Institute. He previously worked at the Children's Hospital of Philadelphia. In January 2008 Tony will assume a second editorial role, as Associate Editor of the American Journal of Mental Retardation. Contact Tony by email at: tjsimon@ucdavis.edu.

THE COUNCIL MEMBERS



Bronwyn Glaser 2009 Council: Professional Member

Bronwyn Glaser is finishing up her Ph.D. in Psychology at the University of Geneva in Switzerland while doing research devoted to understanding social cognition and brain function in VCFS. Since completing her B.A. at Stanford University in 1998, she has been doing clinical research with children affected by neurogenetic syndromes, including velo-cardio-facial syndrome, fragile X syndrome, and Williams syndrome. Her work is now focused on VCFS, and she has worked with VCFS families at Stanford University in California and the University of Geneva, under the mentorship of Allan Reiss and Stephan Eliez. In

2004, Bronwyn earned her M.A. at the University of Denver in Child Clinical Psychology, where she was studying the development of psychopathology. Bronwyn's current doctoral work is focused on face processing in VCFS. After her doctorate, she would like to combine her research and educational interests to develop cognitive remediation therapies for children with atypical developmental trajectories. A native of Northern 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.



Dr. Nathaniel H. Robin, M.D. (FAAP, FABMG)

Dr. Robin is a clinical geneticist at the University of Alabama at Birmingham. He attended Albert Einstein College of Medicine in the Bronx, New York, where he remained as a resident in pediatrics through 1992. It was there that he first met Dr. Shrpintzen and developed an interest in medical genetics. He then proceeded to the Children's Hospital Philadelphia/University of Pennsylvania as a fellow in Human Genetics and Molecular Biology. During this time he furthered his interest in clefting and craniofacial disorders, especially velocardiofacial syndrome. Following his fellowship, he accepted a faculty position in the Department of Genetics at Case Western Reserve University School of Medicine in 1995. In 2003, Dr. Robin joined the Departments of Genetics at UAB. Dr. Robin has been a board member since 2005. For more information on Dr. Robin and the UAB Department of Genetics Programs, please see <http://138.26.45.17/index.htm>.



Merav Burg-Malki

I am the psychologist of the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel. I have been working with families with VCFS and Williams syndrome since the center was established by Dr. Doron Gothelf six years ago. As a part of my clinical work I am involved in the psychological evaluations and the diverse therapies that the center provides (Behavioral modification, Psychotherapy, Parent guidance, Social-sexual education program). I am coordinating 'The Big Brother Program' that operates in our center, a program that helps children develop social skills and adaptive functioning. I am also the editor of the VCFS Israeli newsletter. I have completed clinical child psychology training at Tel Aviv University and today I am a PhD scholar (Israeli President Award) at the Psychology Department, Bar-Ilan University. My research topic is social cognition and social behavior of children with VCFS and Williams syndrome. You are welcome to contact me at: 972-542456-110 or at meravb2@clalit.org.il



Jennifer Stevens, Council, Lay Member

My husband Chris and I have four children, 12 year-old Domenique, 10 year-old Tatiana, 7 year-old Christopher, and 6 year-old Kaya. Christopher was diagnosed with VCFS in November of 2000 just before his first birthday. I have been a stay at home mom for the past 12 years, and have enjoyed volunteering at their elementary school and also as a soccer and baseball coach. We are Jersey Shore natives who love to swim and surf among other things! Families may feel free to contact us at any time at (732)899-0511 or jenstevens2006@comcast.net.



Philippe de Clercq

I am 42 years old and I live in Paris, France. I am married to Frédérique who is the Vice-President of Génération 22 in France and the father of three children, Thibaud, Astrid and Baptiste. Astrid is affected by the VCFS. She is 15 years old and we learned of her affection in 1999. We are heavily involved in 22q11 microdeletion issues, both in terms of support for parents who are confronted with the syndrome and at research level, taking part in protocols such as the one headed by Stephan Eliez, for example. In this spirit of shared experience and inter-parental information, I agreed to sit on the VCFSEF Board.

On a professional level, I am the Chairman of a translation company, and those of you who attended the conference in Strasbourg in 2006 will know that I organised the interpreting services for the event. I was able to meet some of you in Strasbourg and hope to have the opportunity of greeting you all at the next conference. You can reach me at pdeclercq@wordshop.fr.

THE COUNCIL MEMBERS



Amyel Loy

Amyel was born in Rome the 7th of December 1969. She thinks that what makes life meaningful is children and art. That's why she has two children, Giuseppe and Orlando. She is an art historian and writes art books for children. She considers herself a very lucky woman because she discovered that beauty and love can raise only from complexity and effort. She wrote, "Thank you, VCFSEF, for the wonderful opportunity you are giving me to share and learn." Amyel can be reached by email at amyel@libero.it



Robert Shprintzen, Past Executive Director:

This photograph shows me, dripping wet from a rainstorm, at a surprise 60th birthday party last year in Strasbourg, France, the night before the VCFSEF meeting started. I was surrounded by my wife and many friends from Syracuse, Europe, Israel, Mexico, and Australia who were there, probably to let me know that they are all younger than I am. I introduce myself this way so that people know that directions in life are often unpredictable, and had anyone told me 35 years ago when I completed my Ph.D. in speech pathology that I would end up in a winestub in Strasbourg holding a Roman candle with friends who share a vision with me based on a genetic disease, I would not have believed it. After completing my studies, I spent 23 years in New York City as Director of a major craniofacial center and during that time turned my attention almost completely to clinical genetics. At the time, in 1974, it was a brand new field of study and one's educational background was irrelevant. Most people do not know that I actually delineated three other genetic syndrome besides VCFS: Shprintzen-Goldberg craniosynostosis syndrome, Shprintzen-Goldberg omphalocele syndrome, and Goldberg-Shprintzen syndrome. However, it was VCFS that captured my heart and soul, and today at Upstate Medical University in Syracuse, where I have been now for over 10 years, I have had the ability to devote myself to it entirely. My major passions in life are my family (my wife of 36 years, Debby, and children Jodi and Adam) and VCFS with time for little else. I can be reached at shprintr@upstate.edu.



Keri Alexander, Past-President

Hello! I have had the wonderful opportunity to serve as President for the VCFS Foundation this past year. The many inspiring individuals that I have met and worked with will never be forgotten! I will continue to serve this Foundation in any way I can because of the respect I have for it's mission, leaders, members and families.

My husband Steve and I live in Dallas, Texas. We were honored to host the 2007 conference in July. We have 2 sons, Ty(8) and Rhett (5). Rhett has Velo-Cardio-Facial Syndrome. Thanks again to Dr. Karen Golding-Kushner and Dr. Bob Shprintzen for their dedication to our Foundation. I can be reached by email at skalex1@tx.rr.com.

REGIONAL DIRECTORS



Stephan Eliez, Europe

I am the European Regional Director, and have been studying velocardiofacial syndrome since 1993. My initial interest in the syndrome took me from my native Switzerland to Stanford University for a four-year research fellowship and then back to Geneva in 2001 to establish a research and clinical center for families in Europe. In 2005, I became professor at Geneva University Medical School and director of child psychiatry and special education in Geneva. These responsibilities have intensified my interest in detecting early factors that put children at risk for psychological problems, and my general belief in a strong marriage between clinical and research work. One of the early members of the VCFSEF, I am especially dedicated to improving the treatment of VCFS in Europe and strengthening collaborations between regional parent associations and research groups. I can be reached at stephan.eliez@medecine.unige.ch.

REGIONAL DIRECTORS...



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

Hola,

I am Antonio Ysunza, Regional Director for Latin America. I am a medical researcher at the Hospital Gea Gonzalez in Mexico City. In our group, the main professional and research interests are patients with craniofacial anomalies. We receive patients from all over Mexico and we have been working together for more than 20 years. I am a physician specialized in Audiology and Phoniatrics and also a Speech and Language Pathologist.

If you need any information in Spanish (En Español), please do not hesitate to contact me at:



Dianne Altuna, Co-Director, U.S.

What an honor to be a Regional Director for VCFSEF, and to work for an organization that offers support to families and professionals whose lives include individuals with VCFS. As a Speech Pathologist, I work with many children with the syndrome, and have enjoyed each child and family. For the past 20 years, I have worked specifically with individuals with a craniofacial difference in the Los Angeles California and Dallas Texas areas. In addition, I hold a Lecturer position with the University of Texas at Dallas where I have the opportunity to work with graduate students in Speech Pathology. My family includes a very supportive husband, (Patricio) and a wonderful daughter (Gabriela). We live in Dallas with two dogs "Rusty" and "Angel". I look forward to my position as regional director with this organization. Please feel free to contact me at paltuna@aol.com or 214.763.7388.



Donna Landsman, Co-Director, U.S.

I am very excited about serving the foundation through the co-regional director position for the United States and Canada. I have been involved with the foundation as both a speaker on educational issues and a past-president since 1992 when my son was diagnosed with the syndrome. My struggles trying to find educational programs that matched his learning style have led me to focus my efforts on VCFS and educational interventions. I hope to increase awareness in the educational/medical community of the syndrome and work toward developing more effective learning environments for children with VCFS. I have been a teacher in the Middleton-Cross Plains school district at the upper elementary/ middle school levels for more than 30 years and I am also a co-operating teacher with the University of Wisconsin School of Education. I recently published a book, *Educating Children with Velo-Cardio-Facial Syndrome* and I have worked with families and school districts as an educational consultant on VCFS issues. I am currently working with the University of Wisconsin-Extension to plan a series of webcasts focused on VCFS and learning issues.

I live in Madison, Wisconsin with my husband Jeff who is also actively involved with the foundation as treasurer. Our 23 year old son with VCFS lives close by in his own apartment and we also have another son who is married and attending law school in Chicago. You can email me at cutler-landsman@vcfsef.org.



Middle East, Doron Gothelf, MD

I was born and raised in Tel Aviv where I studied Medicine. I have completed residency in Adult and Child and Adolescent Psychiatry and research fellowship in Behavioral Neurogenetics and Neuroimaging at Stanford University. I have always been interested in the genetics of psychiatric disorders and to help improve the life of children and families facing chronic medical conditions. I have been treating and studying individuals with VCFS for 13 years. In 2001 I established the Behavioral Neurogenetics Center at Schneider Children's Medical Center of Israel. The center is unique in that it combines a comprehensive clinical program with research. Besides VCFS we 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 main aim of our research program is to understand the pathways leading from the genetic defect to the neuropsychiatric phenotype of VCFS. We hope this will lead to finding better treatments for the neuropsychiatric and cognitive deficits of children and adults with VCFS. He can be reached by email at gothelf@post.tau.ac.il or by phone: +972-3-922-7415.

REGIONAL DIRECTORS...



Steve Russell

I am the Educational Foundation's Regional Director for Australia and Asia. I am the President of and, with Kathy Russell, founded the VCFS Foundation of Queensland, in Australia in 1997. The Foundation is based in Brisbane, on the east coast.

Our daughter Amy was diagnosed in Brisbane when she was three - after surgery to repair her cleft palate. Like many parents, we were seeking information, but found that there was not much known about the syndrome - and there were no support groups. Today, the VCFS Foundation of Queensland has, in partnership with the Mater Children's Hospital, established the VCFS Centre at the Mater - a multi-disciplinary centre for the diagnosis, treatment and research of VCFS in Australia. I am a lawyer in private practice in Brisbane and sit on the Advisory Board of the VCFS Centre at the Mater. I play half back for a Golden Oldies Rugby team in Brisbane. I have been active in the Educational Foundation, and have attended almost every meeting since Milwaukee in 1999. Contact me at: srussell@russellandcompany.com.au.

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Two Dallas Cowboy Cheerleaders autograph photos for awaiting children during the Friday night dinner in Plano, TX.

GLOBAL FORUM

Moderator: Cheryl Dultz, parent and educator & Joel Johnson, MD

Welcome to the current edition of the Global Community Forum. The Forum's purpose is to collect and archive ideas from the community on important subjects that are related to VCFS. Each forum will begin with a brief introduction to the topic. This will be followed by representative comments, selected by the Moderator, from members of the community around the globe who have written to us. We will strive to print as many responses as we can and represent as many views as possible. The views presented are not necessarily endorsed by the editorial staff or the Foundation but we hope they will foster communication. Please note that we cannot print solicitations or direct medical advice. However it is okay to discuss your own medical experiences. We advise that all personal information is removed. If medical information is shared, we reserve the right to remove any identifying information. We also reserve the right to edit responses for clarity and grammar, but will not change the content.

The Question

We asked community members about their experiences in finding knowledgeable healthcare providers or how they have educated the providers to whom they had access. We sought out responses that highlighted the differences between large cities and small towns and the perspectives from different countries. We included personal narratives about positives and negatives of finding informed care. However, the Foundation is not able to publish the names of specific doctors or hospitals so those were removed.

The Responses

From North Carolina:

I am a parent of a ten-year-old child with VCFS. We live in North Carolina and have had excellent care since my child's was diagnosis at age 2. I have never had a problem in finding care because we live one hour and fifteen minutes away from a University Medical Center in Winston-Salem, NC. Our geneticist is well informed and the hospital staff with whom we have had contact have been excellent. I have not attempted to use other options in my hometown since this major medical center is within driving distance.

From Adelaide, South Australia:

In 1993, my son and I were patients at the local Hospital. Our doctor happened to be a friend of an international expert in the field who referred us to a geneticist at the hospital. The geneticist was very knowledgeable about VCFS and very approachable. Also as you may be aware, the VCFS Foundation of Queensland in conjunction opened the first VCFS Clinic in Australia last year at a major Brisbane children's hospital. This will be of great benefit to families with VCFS children.

From Moscow, Idaho:

Our daughter was born with esophageal atresia with a tracheal-esophageal fistula, which was repaired in Boise, Idaho when she was just a day old. About one month later, we took her home with a feeding tube. We worked with a local pediatrician in Pullman, Washington to provide the best possible care for her. The experience turned out to be devastating. A home health nurse visit revealed that our daughter was retracting. We took her to the doctor immediately. The doctor's response was that she was breathing just fine. One week later, we took our daughter back to Boise, Idaho to follow up with a cardiologist there. The cardiologist was alarmed that our daughter was struggling to breathe, evidenced by the degree to which she was retracting. The cardiologist delivered the devastating news that our daughter was in heart failure. This was frustrating because of our diligence in visiting our pediatrician. Despite its challenges, some good did come out of this situation. The cardiologist referred us to pediatricians in the Boise, Idaho area who would be ideal candidates to provide care for our medically fragile daughter. Our new team of doctors gives us comfort because they have knowledge about this condition and provide the best possible care for our daughter. Our new pediatrician referred us to resources available for our daughter. This doctor has stayed current on the latest research and uses the best practices approach for our daughter. On the flip side, we have experienced some "downs" outside of our regular circle of health care professionals. On a couple of occasions, we have had visits to our local emergency room in Boise. With the exception of one time, we had to describe the syndrome to the primary physician and cite characteristics that were relevant to the current situation. We have dealt with other health care providers including physical, occupational, and speech therapists for our daughter. The occupational and speech therapists that we worked with were knowledgeable about our daughter's condition. This was an exceptional experience for us because they had worked with other children with similar problems and with VCFS. In response to this effort to explore the differences in obtaining knowledgeable health care providers in rural and urban communities, our experiences have proved to us that health care providers in small towns are not equipped to deal with children with VCFS, particularly those in central to northern Idaho. Another important aspect we have learned in seeking qualified and knowledgeable health care providers specific to this diagnosis is that by networking with other affected families and specialized doctors, such as our pediatric cardiologist and surgeon, we can find out about who are good providers for our kids.

From Madison, Wisconsin:

The medical community in Madison is quite uninformed about VCFS. Our child's doctors have learned about the syndrome primarily through the information we have provided to them. It is still quite common for us to go to urgent care for a problem and have the physician know nothing about the syndrome. In fact, the local leading immunologist was not aware of VCFS, although he had

GLOBAL FORUM

heard of DiGeorge. To his knowledge there are not many children diagnosed with this at our local university hospital. Our child's cardiologist, ENT physician, cornea specialist, endocrine doctor, and primary physician all had virtually no knowledge of VCFS before meeting our son. To their credit, they have all been quite interested, helpful and we feel our son's treatment has been good. Our son's psychiatrist was also not aware of VCFS, but after treating our child he has worked with others with the syndrome in his practice. The general perception is that VCFS is a very rare disorder and there is not a big push to get information into the community. I would love to change this perception. I have considered going to the administration of the hospital to push for more staff education, but I haven't done that at this point. I most likely will make that move sometime this year.

From St. Albert, Alberta, Canada:

We are from St. Albert, Alberta, Canada. Our medical care is predominantly out of Edmonton, AB. Our daughter is 4 1/2, and was diagnosed with VCFS at 22 months of age. She was diagnosed by a cardiologist who was educated enough to do the FISH test after seeing her for the first time. Up until that point we had been very frustrated because we needed to know what was wrong. We had been seeing many specialists at a University Hospital for her various difficulties. They did not know enough to consider VCFS. We saw a nephrologist, a gastroenterologist, a pulmonary specialist, a pediatrician, an O.T. for swallowing, E.R. pediatricians, and a palate specialist/surgeon. I was in a high-risk clinic during my pregnancy because of kidney cysts seen in utero. After diagnosis, genetics and a rehab hospital were added to that list. The rehab hospital was helpful in some areas but knew nothing specific about VCFS. However, during a routine check and immunization visit when our daughter was 12 months, I met a nurse at the health clinic who had worked in genetics prior to our visit. After hearing our daughter's history, she suggested that we ask our doctors for genetic testing. I did so at our next appointment. The doctor literally rolled his eyes and laughed, saying, "No, your daughter does not need genetic tests". I never brought it up again!

The specialists seem to focus on their area of expertise and not collaborate to see the bigger picture. However, our cardiologist told us she was testing our daughter for 'Catch 22'. We found out later that Catch 22 is a name that is no longer used. We could not find information under that name and we were left in limbo for about 3 weeks. I contacted a friend who is a genetic counselor and got our first information on paper. Other than what we could find on our own at the time via Internet, our medical community has never given us any information. I searched for a pediatrician who I knew was familiar with special needs children. Our new pediatrician gives us support on certain issues, our medical needs are not huge.

I work in healthcare as a Respiratory Therapist and know about working the system. I have also made contacts, and been able to speed up the process in some areas of our daughter's healthcare. I pushed a lot! I believe that people with less knowledge of the healthcare system, or without contacts, are at a disadvantage in Canada. Parents who know to push and keep asking get further. This is unfortunate for those who do not how to push. We have since attended one conference in Toronto and plan on attending others. We receive many newsletters and have ordered all the books that we know of on VCFS. I have given much of that information to our physicians here. I know we have a long way to go in educating the medical community and education system. I am doing bits and pieces here as I learn.

Moderators' Perspective

The comments in this Forum illustrate the many problems that parents face when trying to find health care providers for children with VCFS. It would appear that major university medical school hospitals are more likely to have physicians who have a knowledge base of the syndrome. Where does that leave the parents who live in rural areas? While knowledge of the syndrome is important, perhaps the most important quality for a parent to seek in a physician is compassion and the desire to be educated about the deletion and its consequences. A physician who is willing to help and seek assistance is as valuable as a physician who has a working knowledge of VCFS.

Does that mean parents must do it all? Yes and no... The good news is that there are foundations and support groups that can provide information to guide parents while they advocate for their children. Partnerships and networking is key in helping children with VCFS. From Australia to Canada the message was the same; when parents partner with physicians and researchers, their children will receive better care. By working together we can create a knowledge base for our children who have the deletion. And as we know at the VCFS Educational Foundation... Knowledge is hope.

Editor's Note:

To assist further in this process, VCFSEF has just produced an informational brochure that was funded by the The Amanda McPherson Fund of the VCFS Educational Foundation. Copies are being mailed to a large number of physicians, hospital and medical organizations. One can order brochures free of charge at www.vcfsef.org or by calling 1-866-VCFSEF5; international callers dial 1-723-238-8803. Parents may want to get several of these to give to the clinicians, educators and other professionals with whom they work.

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Above, Dr. Karen Golding-Kushner stand with Quinn Bradlee after he presented the new VCFS documentary that he produced.



Right, Mrs. Mary Macpherson addresses the conference before unveiling the new, "Knowledge is Hope" VCFSEF brochure.

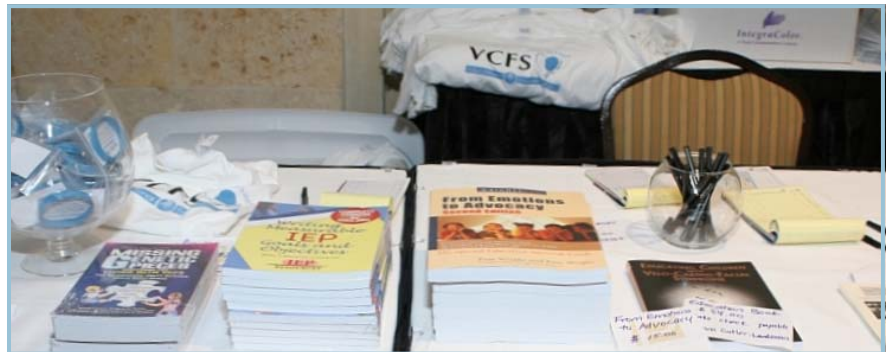


Dr. Tony Simon and Leeza Gabriel review sign-ups for their study

2008 Conference

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02	Variable expression of VCFS: what explains differences in severity? <i>Alan Shanske, M.D.</i> Questions and discussion Feeding, growth, and weight gain in VCFS <i>Robert Beecher</i>
03	An Anatomical and Physiological Explanation of Velopharyngeal Function <i>Antonio Ysunza, M.D.</i> Surgical Planning for Hypernasal Speech: 35 Years Studying Outcomes <i>Robert J. Shprintzen, Ph.D.</i> Questions and Discussion
04	Special Panel Session: Come Blow Your Horn: Why DO They Call It SPEECH Therapy and Are Children with VCFS Dyspraxic? <i>Dianne Altuna, M.S., Karen J. Golding-Kushner, Ph.D., Robert J. Shprintzen, Ph.D., Susan Marks, M.S. Moderator</i>
05	Phonologic Approach to Speech and Language Development in Young children with VPI and VCFS <i>Virginia Dixon-Wood, M.A.</i> Eliminating abnormal compensatory articulation patterns in VCFS: treatment and outcomes <i>Karen J. Golding-Kushner, Ph.D.</i>
06	What do you do when you can't find a speech therapist? <i>Sandra Ochoa</i> Teletherapy: using technology to solve the problem <i>Karen J. Golding-Kushner, Ph.D.</i> Intensive Speech Therapy in a Summer Camp Setting <i>Dianne Altuna, M.S.</i> Questions and Discussion
07	Leg Pains in VCFS <i>Ahmad Al-Khattat, Ph.D.</i> Questions and discussion
08	Genetic Modifiers and Genetic Susceptibility in VCFS <i>Bernice Morrow, Ph.D.</i> Microarray-based analyses of VCFS <i>Frank Middleton, Ph.D.</i>
09	Neural Imaging, Behavior, and Genomic Analysis: From Genes to Brain to Behavior <i>Wendy Kates, Ph.D.</i> Questions and Discussion
10	Progress toward building a better model of the human disease: Tbx1 dosage modulation in mice <i>Antonio Baldini, M.D.</i> Can we model behavioral/psychiatric disorder in laboratory animals? <i>Elizabeth Illingworth, Ph.D.</i>
11	Investigating a potential modifier of VCFS in mice <i>Anne Moon, M.D., Ph.D. -PENDING</i> Questions and discussion
12	Problems with space, time and numbers: A new mind and brain explanation <i>Tony J. Simon, Ph.D.</i>
13	Face processing and social impairments in VCFS <i>Bronwyn Glaser, M.A.</i> Questions and Discussion
14	Longitudinal perspective on genes, brain and behavior in VCFS <i>Doron Gothelf</i> Autism in neurogenetic syndromes <i>Doron Gothelf</i>
15	Functional Imaging of Cognition and Emotion in VCFS <i>Wendy Kates, Ph.D.</i>
16	Educational Interventions for Children with VCFS <i>Donna Cutler-Landsman, M.A.</i> Questions and Discussion
17	Developing a drug for psychiatric disorders in children and adults: From Planning to Approval <i>Stuart Kushner, M.D.</i> Questions and Discussion
18	Panel: The Autism Controversy <i>Doron Gothelf, M.D., Wendy Kates, Ph.D., Frank Middleton, Ph.D., Tony J. Simon, Ph.D.</i> The smile that changed our world <i>Jennifer Stevens</i>
19	Orthodontic management in VCFS <i>James Mulick, D.D.S.</i> Sleep Disturbance in children with VCFS <i>Robert J. Shprintzen, Ph.D.</i> Questions and Discussion