



VCFSEF NEWS

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Editor
Design & Layout

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RAYS OF HOPE

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We hope you enjoy our newest addition to the VCFS Educational Foundation newsletter – Rays of Hope! Raising and caring for children who face challenges that most children will never encounter can be overwhelming. And *sometimes*, in the midst of scheduling physician visits, therapies, hospital visits, and planning IEPs, we lose sight of how inspirational our children truly are. Their strength, talents and tenacity frequently amaze those around them. Although I am not one who usually quotes cartoon characters, one of my favorite sayings is from the Disney movie *Mulan*. “The flower that blooms in adversity is the most rare and beautiful of all.” Our children are rare and beautiful flowers!

Michael
Submitted by Robin

My son, Michael, is thirteen years old. He has VCFS with a heart defect, no thymus and learning difficulties. His first five years were difficult, to say the least. Michael had two open-heart surgeries and numerous hospitalizations for illnesses. But he survived it all. God’s plan was not complete.

While we were trying to figure out what type of life he would have, Michael led the way. Watching his big sister play soccer, he decided he wanted to play too. The doctor was pretty iffy about that but we thought, “What would it hurt if he tried?” Eight years later, the Doctor is amazed at Michael’s progress.

Michael’s biggest accomplishment (from a sports standpoint) was when he was ten years old. The soccer field size increases at that age, and he was feeling it. Running with an oversized heart and other complications, was not easy for him. Without any prior conversation about this, Michael came to me and said, “ I think I want to be a

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SAVE THE DATES!
...for the International Scientific Conferences
Info on our web site:

- **2006:**
July 7-9, 2006
Strasbourg, France
- **2006:**
November 2-4, 2006
Brisbane, Australia
- **2007**
July 20-22
Dallas, Tx

RAYS OF HOPE ...

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goalie. I'm having trouble running the field." Wow! OK! He had never played goalie before, so we found a goalie coach. Today, Michael is a fabulous goalie. He still plays left forward also and loves it. The field is A LOT larger now and it's a task to run it... but does he try? Heck, yes!

Michael's cardiologist is impressed. He meets obstacles head on. It has been Michael's philosophy that he has to learn his own limitations - read his own body. Nobody can do that for him. He knows when to stop when it gets to be too much. His coaches are also impressed ... sometimes in awe. So am I.

Michael LOVES sports! He loves to swim, play handball, basketball and, of course, soccer. He would LOVE to play football, but that is one limitation we have imposed. Kids often-times know what they need and I am glad we listened and moved forward. I have attached an awesome picture of Michael swatting away an attempted goal! Thank you for letting me share.



Michael going all-out for the save!!!

If you would like to submit a "Rays of Hope" story about a child with VCFS, please contact Maureen Anderson at mladja@aol.com or by regular mail via the Foundation office.

Glenn

Submitted by Joe Abruzzi

I'd like to share some positive experiences about my son, Glenn. At age 26 he has persevered for ten years to finally get his driver's license. After years of failed driver's ed classes, private lessons, 'Dad' lessons, and failed written tests, he finally passed the written test and got a chance at the road test. Unfortunately he was overwhelmed by an impatient tester and failed. Glenn regrouped, took a few more lessons and came back to take just the road test, feeling that at least the one hurdle was behind him after three tries. When he showed up for the 2nd road test he was informed that he must take the written test again because too many days had elapsed since his last test. He fell apart initially but was so determined that he mustered up the will and took the written again and passed. But he failed the vision test because he lost his glasses and wasn't allowed to take the road test. Could he recover from this last disappointment? Next stop, the Mall for a new eye exam and glasses. Now he was ready to face the DMV yet again. On that day, he

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RAYS OF HOPE ...

Glenn continued from Page 2

didn't have to take the written again, passed the vision test with his new specs, and passed the road test. I've never seen him show so much determination!

Also, during this past year, Glenn has turned a hobby into a business. Once a month he DJ's for a dance given by an agency that supports several group homes. It's a sight to behold! Glenn spins tunes on this equipment (that I would have trouble turning on and off) with a concentration that I've never observed with him before. And the clients at the dance have the time of their lives.

Have we had some rough days this year? Sure. But these are the bright spots that I'd like to share with folks who can understand our experiences.

Kati Jane

Submitted by Jaime and Paul

This is our daughter, pictured at right, Kati Jane who has VCFS and is seven years old in this picture. Kati is proudly displaying her bib number and medal of completion of The Big Sur International Marathon (5K) in 2005. She and I were going to "walk" the 5k but when the gun went off Kati surprised me and took off running! She ran most of the way. She will return for the 5k once again in 2006.

Tara

Submitted by Janine

I wanted to let you know some exciting news about my daughter, Tara. A twelve year old, 6th grader, Tara was diagnosed at birth with VCFS. We recently moved to Tucson, Arizona from Ohio. Back in Ohio, Tara was struggling in school and had very few friends, if any at all. Tara has a very hard time making friends. Since we moved to Arizona, her grades have improved dramatically and she has made a friend or two. She has even made the A/B Honor Roll twice this year in school!!



Kati Jane proudly displaying her medal

Beth

I am excited and proud to tell you all that my wonderful daughter, Beth (Elizabeth), has been accepted into college this fall !!!!! School has been sometimes difficult for Beth. She struggles with math and complicated concepts. She needs things explained to her in depth and at times that has been very hard to get through to the school and teachers. With Beth's IEP (Individual Education Plan) we have tried to give her as much independence as possible but still have support. Since we moved to California two years ago, Beth has excelled in areas in which she had so many prior problems.

I am extremely proud of Beth and will be very happy to see her go to college and do her best, as I know she will. I, of course, will be here to help if she wants it and I know she will succeed in whatever she sets her sights on!

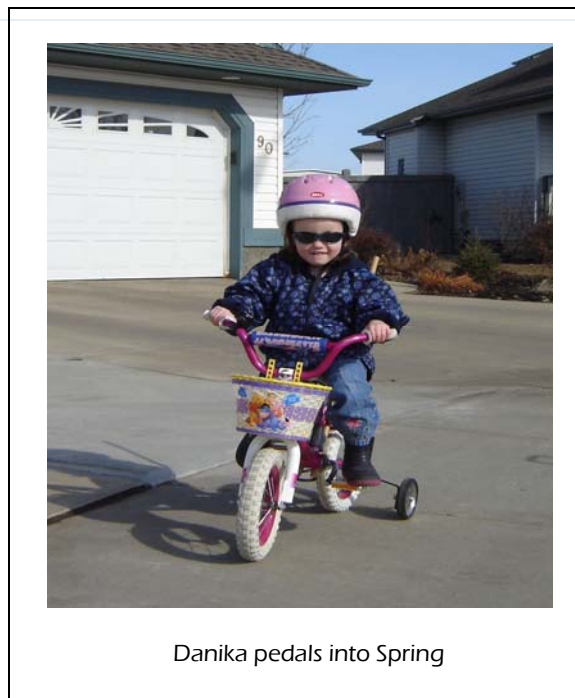
Thank you for letting me share how proud I am!

RAYS OF HOPE ...

Danika

Submitted by Chandra

Just wanted to share some good things we see happening with our daughter, Danika, who will be 4 this June. She was diagnosed with VCFS two years ago, and, although she has not suffered life threatening medical problems, she has still had her share of issues. Lack of muscle tone is a big challenge for her, as she often has leg pains, falls far too often, and is physically and emotionally exhausted by the end of a day. Danika loves keeping active, though, and is working on her balance and strength. She regularly takes gymnastics, dance and swimming. Her biggest accomplishment this spring is to begin riding her bike on her own and follow her big sister down the sidewalk. Now that the snow is gone, she asks everyday to ride her bike! It is such a joy for us to see her excitement as she gains bits of independence. I have attached a photo of Danika on her bike.



Danika pedals into Spring

Isiah

Submitted by Melanie

Hello to all! I want to share some good news! After a year of being told that my son, Isiah Carrera, would not be able to master his kindergarten material, his teacher informed me that he is one of her top students. He has also begun to comprehend first grade level already. Considering all the school Isiah has missed with doctor visits, heart surgery, and Iga deficiency, that is outstanding news for us! Hope you can enjoy our small success story as much as we have!!

AROUND THE WORLD NOTES

Continental Europe

By Bronwyn Glaser

University of Geneva Medical School

Dominique Pfeiffer, of the French group, Generation 22, and co-chair of the planning committee for the upcoming International Scientific Meeting of the VCFSEF, reports that preparations for the Strasbourg conference are coming along nicely. Many of the 350 Generation22 families have signed up along with their children! Dominique Pfeiffer especially encourages registration from regions other than France, and reiterates that the entire program will be in French and English, which will help make it more accessible to all participants.

Ahmed Al-Khattat, VCFSEF Co-Regional Director for the United Kingdom writes, "I would like to introduce Mrs. Julie Wooton to you. Julie is the founder and organizer of "Max Appeal", currently the most active 22q11 deletion

support group in the UK. Julie has been very active in information dissemination and promotion of the condition both domestically and internationally. She produces a brilliant newsletter of a very high standard and organizes a number of annual events and meetings throughout the UK. Julie has kindly agreed to accept the position of the co-Director for the UK office of the VCFSEF and I am sure she will execute this post to the highest feasible standard. I would be grateful if you would include her in your future correspondence.

Her e-mail address is: julie@maxappeal.org.uk

Rene Olsen and Sarah Demerbes of the newly founded Danish parent association report that they already have 82 members, representing 21 families. In addition to representatives from families, Maria Boers, a speech pathologist, is a part of the organization. They are looking to find other doctors/professional specialists to include in their

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EXECUTIVE DIRECTOR REPORT

Karen Golding-Kushner, Ph.D.

This is a very exciting time for the Velo-cardio-Facial Syndrome Educational Foundation. The Program for our 12th International Scientific Meeting to be held this July in Strasbourg is nearly complete and it promises to be an outstanding conference. The distinguished faculty includes over 50 speakers from 20 countries, many of whom will be familiar to our professional and lay participants. We also welcome many new speakers. New programs will include a special poster session in which clinical programs in Europe and around the world will present their services and teams, and an international panel to address best-practice for children and adults with VCFS including timing and sequencing of evaluations and treatment. All presentations will be heard simultaneously in English and French, and slides are being translated for simultaneous bilingual presentation, as well. Look for more details inside! The Planning Committee for our 13th Meeting, to be held this November in Brisbane, Australia, is also busy working on the scientific program and social events. Details are elsewhere in this newsletter. We are also completing a new brochure about VCFS that we plan to have in the hands of pediatricians and geneticists in the near future.

We are also very grateful to the sisters of Sigma Alpha Iota sorority of the Hartt School who chose the VCFS Educational Foundation as the beneficiary of their annual fund raiser. Amy Dotson, who chaired the event, wrote an article for this issue describing the benefit and the way in which they educated an entire community about VCFS. What a wonderful way to help us fulfill our mission!

We welcome Julie Wooten as our new co-Regional Direc-

tor for the UK. She will be working with Ahmad Al-Khattat, her co-Director, and Stephan Eliez, Regional Director of the VCFSEF for Europe to keep lines of communication and the flow of information open. Thank you to Julie Squair, who served in that role for the last few years.

Our web site has had a facelift and the website and email have moved to a new host. This caused some lost correspondence and frustration, but our web master, Kelvin Ringold, has gotten it all back under control. If you sent an email to info@vcfsef.org or to me at kgkushner@vcfsef.org in the last month or two and did not have a reply, please write again. We may not have received your mail. Thank you for your patience.

We loved hearing how much you appreciated our last newsletter- thank you for your emails and phone calls, and kudos again to our Editor, Eileen Marrinan for her dedication. I am confident you will find as much interesting and useful information in this issue.

See you in Strasbourg!



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://vcfsef.org/Donations/wrist.html>. Online payments are processed through PayPal.

For questions regarding wrist bands, contact Nancy Robbins at nrobbins@aol.com.



A WORD FROM THE PRESIDENT...

Steve Russell
President, VCFSEF

There are several things which are very significant for the VCFS Educational Foundation, arising from this President's report from Australia. The first is that the Foundation's president is an Australian. Over three years ago, the executive and board of the Foundation formally inaugurated international regional directors. This was a truly visionary step. At the same time the board and the executive both foresaw and provided for the international growth of the Foundation.

As the regional directors were appointed and grew into their roles, so too did the Educational Foundation grow. I have personally witnessed the steady and strong growth of the Foundation over this period, manifested (for me and I'm sure many others) in the increasing numbers of attendees at the annual meeting, and the truly remarkable increase in the interest in VCFS, and the quality and competence of research and other papers which the faculty at those meetings have presented year after year.

The second thing is that the Foundation is managing its international growth very well. The first non-US based president of the Foundation was Julie Squair of the UK. But continental Europe has not been left out either - it was (literally) a toss of the coin between my nomination and that of Dominique Pfeiffer, who with Jean-Luis, is the driving force for the local arrangements for the July 2006 conference in Strasbourg.

Thirdly, although I can't pretend that it's been easy discharging the presidency from half way around the world from the Foundation's main office, it is a tribute to the commitment and organisation of the current board and executive that things have gone as relatively smoothly as they have. I want to acknowledge the work of all of my fellow board members, and the executive of the Foundation, for their dedication and work thus far through the year; and to say how much I am looking forward to both the Strasbourg and Brisbane meetings. My involvement as President has not been limited to assisting in the organisation of the conference in Brisbane in November, 2006; and I can assure all members and readers that the professional members of the board and executive in particular spend a great deal of time on the day to day management of the business and operations of the Foundation. Not a day goes by without

Dr Golding-Kushner attending to correspondence, on the phone or doing something else for the benefit of the members of the Educational Foundation, and ultimately for all VCFS patients.

At the time of preparing this article, I haven't seen a draft of this Newsletter, but I know it will be a bumper issue (thanks to the very considerable efforts of editor, Eileen Marrinan, who must be one of the most patient editors in the world) and this, too, bodes very well for the immediate and long term future of the Educational Foundation in achieving its mission. I hope this Newsletter finds you all well and I look forward to seeing those of you who are going to Strasbourg there in la belle France; and even more (apologies to Dominique and Jean-Luis Pfeiffer) to seeing those of you who will make the drip Down Under in November, 2006.



Steve Russell

Call for Newsletter Submissions

The VCFS Educational Foundation wishes to reflect the views and experiences of a wide variety of its lay and professional members. Please contact the Editor, Eileen Marrinan at 315-464-6580 or via email to marrinae@upstate.edu with your ideas or submissions.

Look on the web site for translations into Arabic, Hebrew and Spanish.

AROUND THE WORLD NOTES

organization. Moreover, to become familiar with the specific issues that Danish families are encountering, they have distributed a survey to their members. The results of the survey will be used to target specific issues and points of discussion for the 22q11 patients and families in the future. The first members' weekend will be in May. Detailed information and the structure of the organization have been posted on the website at: www.22q11.dk. A more detailed presentation about this new chapter will be given at Strasbourg.

Latin America

By Antonio Ysunza, MS, ScD, Reg Dir

Greetings from Latin America! So far we have a support group in Argentina and another one in Merida (Mexico). These two groups have been very active. They have provided information, orientation and support to many families not only in their own countries but also to other Spanish speaking families from Latin America and even in the US. The newsletter will be translated as usual. If anyone in the foundation knows someone who needs assistance in Spanish, do not hesitate to contact me at

amysunza@terra.com.mx

Middle East

By Doran Gothelf, M.D.

Middle East Regional Director & Merav Berg

Time goes by quickly and our young neurogenetics center in Israel is already six years old. The center was established thanks to the major support of the late Dr. Donald Cohen, and of Hilda and Philippe Setton.

Inspired by Dr. Robert Shprintzen we created a center that combines research and treatment. We basically wanted to establish a 'warm home' for individuals with VCFS and other neurogenetics syndromes and their families. We feel privileged to having given the opportunity to follow and support the growth and maturation of individuals with VCFS. We are with them when they have to undergo cardiac operation or when the schoolteacher needs advice about learning and behavioral issues concerning the child. We also share their

joy when they celebrate Bar Mitzvah, marry and give birth.

The center has grown and treats about 250 individuals with VCFS and other syndromes. We have been running successful treatment programs including coordination of all medical treatment in one day and under one roof, a 'big brother' program, social-sexual education program, and annual family days.

A special goal of our center is to make a bridge to peace. About 20% of the children treated in the clinic are Arabs. In collaboration with Dr. Muhamd Mahajna, this year our center organized workshops in Arabic for parents and for professionals of the Arab population.

Recently Merav Burg has edited the first issue of the Israeli VCFS Newsletter. Below is the front page of the newsletter showing a very cute 9 years old boy, Amit, diagnosed with VCFS. Amit shared with the readers his hobbies that include sports, cooking and reading books.

Australia & Pacific Rim

By Steve Russell, President

VCFS Foundation of Queensland

VCFS Educational Foundation Inc.

I'm wearing my "Regional Director: Australia/Asia" hat for this article. Most of my work is (I'm sorry to report) confined to the Australian continent, although we have been trying to encourage the establishment of a group in New Zealand. The VCFS movement in Australia continues to be led by the Queensland Foundation (see the article in this newsletter) and supported by Raymond and Ruth Tanner's group in South Australia. For those of you who may not be aware, the Australian landmass is a little bigger than mainland USA, but our population is only 20 million people. So, there is lots of space between the populated centres.

This also means that our VCFS population is, although no doubt proportionally the same as elsewhere in the world, a little more difficult to identify. There are I think, two reasons for this. The first is that the medical and therapeutic professions in Australia are only beginning to

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come up to speed with the existence and prevalence of VCFS; and with the latest in research and treatment techniques from around the world. That said, however, great strides have been made in the last few years and, especially with the establishment of the VCFS Centre at the Mater Children's Hospital in Brisbane, we will no doubt be on track with the rest of the world very soon. The second reason is that because Australia is such a big place, getting around is a challenge in itself. Of course, technological advances in communication in the last ten years or so have shrunk the whole world, and Australia as well.

From an Australian perspective, the big news is no doubt the establishment of the VCFS Centre at the Mater Children's Hospital. The Queensland Minister for Health, Mr Stephen Robertson, conducted a formal opening ceremony at the VCFS Centre at the Mater on Monday, 15 May, 2006.

I would here like to record some very special thanks to the members of the Management Committee of the Queensland VCFS Foundation who have worked tirelessly to see this dream become a reality. The VCFS Centre opened unofficially and began to see patients in November, 2005, but the pace has really quickened since then. Patient numbers doubled in the second quarter over the first quarter of operation.

I also wish to thank Professor Brett McDermott, Director of Kids in Mind (of the Child and Youth Mental Health Service at the Mater Children's Hospital at Brisbane), who took an idea from a bunch of lay people who thought they knew what they wanted and, over a period of two years, shaped it into a very respectable medical reality. Brett is one of the busiest people you will ever meet, but he has given so unselfishly of his time that I often sit back and simply think, "Wow!". Let me also acknowledge the work of Doctor Honey Heussler, a Developmental Paediatrician who is now Director of the VCFS Centre at the Mater. Honey's enthusiasm for the work of VCFS is infectious and all patients and their families have given very warm and positive reports of their experiences with Dr Heussler. I am also pleased and grateful to report that both Brett and Honey

have worked on the Professional Program Committee for the Brisbane conference, although Brett has had to retire very recently because even he has recognised that he has simply taken on too much.

In the meantime, the Queensland Foundation continues its usual work and in addition to planning the local arrangements for the November meeting, is also working on the annual VCFS Faces of Sunshine Ball which will be held on Saturday 4 November, 2006 (to coincide with the last day of the conference). This is a gala black tie evening not to be missed.

The Queensland Foundation also recently staged a very successful Ladies' Spring Lunch at a fine restaurant here in Brisbane. Over 180 ladies attended this lunch on a sunny winter Friday and over \$5,000.00 was raised from the generosity of those good women. Thanks especially go to Kathy Russell and Doreen Innes for their work in organising and staging the lunch. All of the funds raised will go to the operations of the VCFS Centre at the Mater.

Undoubtedly, a rather neglected area of my responsibilities as Australian/Asian Regional Director is the South East Asian region. I will be doing everything I can to spread the word about VCFS Down Under throughout South East Asia, and attracting both faculty and VCFS families to Brisbane in November, 2006.

Another notable development is that Mr Raymond Tanner of South Australia (himself a VCFS patient) has succeeded in registering VCFS on the Australian Government's list of recognised genetic syndromes which qualify for social security assistance in the Australian Medicare system. Outsiders might find it surprising, but I'm sure you as people intimately involved in the VCFS community will not be too surprised to hear that VCFS wasn't even on the list of syndromes which qualify for health assistance in the Medicare system run by the Australian Government. Recognition of VCFS in that system was one of our major goals; now for the private health funds! Raymond's achievement here is all the more notable because of his quiet persistence. Thank you and congratulations go to Raymond for his

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efforts.

Aside from that, we continue in our efforts to raise the profile of VCFS generally in the medical profession in the community at large; and we have been concentrating in particular on the Queensland Health Department, in various ways.

In summary all is well Down Under - as I write this article, it is a beautiful sunny day in winter. I can confidently promise brilliant weather in November (it will be late spring); the surf will be up, the cockatoos screeching and the kangaroos hopping. For those who haven't visited Australia yet, take it from your Regional Director - VCFS Down Under in November, 2006 must not be missed! See ya there, mate!

MEET JULIE WOOTEN

New Regional Director, United Kingdom

Hello! Bonjour! Guten Tag! Dzien dobry! Buenas diaz! Buon giorno! (I don't know any more "hellos!" Sorry to all the nations I've missed!)

I am Julie Wootton, chairman of Max Appeal! UK support group. Following the death of our son, Max, in 1999 the support group was set up by my husband Paul and me with four other families with a child with 22q11.2 deletion. Charitable status was achieved in 2000 and the group swiftly became an accepted source of information and support around the UK and abroad. Max Appeal continues to grow with our income last year being almost £40,000; and we need every penny of it! We are very lucky to have a competent and diverse board of trustees who are all actively involved, along with a lively cohort of volunteers and helpers.

Paul and I have been blessed with Max, and two very robust and healthy children; Georgia aged 12 years and Archie aged 6 years. They give us lots of pleasure, dirty washing and hours sitting in the car hanging around outside various clubs and after-school activities.

We live in Stourbridge in the West Midlands of England where Paul has a house building company. In my 'previous life' I worked as property surveyor in Worcestershire, I have a degree in Housing and qualifications from the Chartered Institute of Housing and the Royal Institution of Chartered Surveyors. When Georgia was toddler I worked part-time writing studies on contaminated land around the Black Country and other parts of Britain which was very interesting. I have not had the commitment of "gainful employ-



ment" since I was expecting Max in 1998 which means that I am now in the fortunate position of being able to give all of my child-free hours for charity work.

Since 2003 I have also been chair of trustees for the Children's Heart Federation which is an umbrella charity for all charities in the UK for children with heart defects and has 19 member organisations including Max Appeal. CHF is a much larger charity (but still small in the scheme of things) with an income of around £600,000 a year and involves a lot of political work relating to cardiac standards as well as direct services to families.

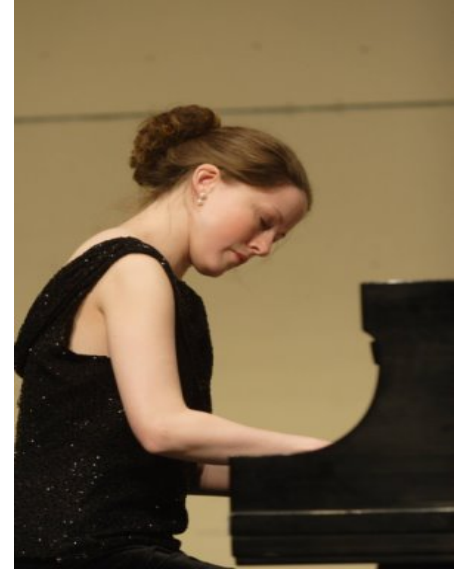
I am very much looking forward to the challenge of being UK representative with Ahmad, and hope to meet as many of you as possible in the future. You can reach Julie Wooten at julie@maxappeal.org.uk

BENEFIT FOR LIFE FUNDRAISER

Amy Dotson

On March 5, 2006 the sisters of Sigma Alpha Iota held their 5th annual *Benefit for Life* in support of the Velo-Cardio-Facial Syndrome Educational Foundation. The afternoon's concert included performers from the Hartt School and guest pianists Karen Ruckman Lindsay and Thomas Ice. The event began with an address from University of Hartford president, Walter Harrison and continued with an hour of music ranging from a jazz trumpet to classical vocalists and everything in between. Lisa Jennings, treasurer of the Educational Foundation spoke to the audience of students, faculty, family and friends about VCFS and the role of the Educational Foundation. Sigma Alpha Iota is proud to announce that the event raised \$9,157.

While we are proud to have raised this money, the most exciting part of the event can not be marked by a number. Before the *Benefit for Life*, Velo-Cardio-Facial Syndrome was virtually unheard of on our campus. The sisters of Sigma Alpha Iota made it a priority to learn about the disorder and teach others using informational pamphlets, the VCFS wristbands and business cards and informational sessions. You would now be hard-pressed to find an organization on campus that has not heard of the syndrome. Even today, two months after the concert, you will see the blue wrist band on the arms of some students.



VCFS member Karen Ruckman Lindsay

Sigma Alpha Iota would like to thank everyone in the Educational Foundation for their support, especially Lisa Jennings, Nancy Robbins and the Southwick Family. Thank you for all of your notes and donations. Each one was appreciated and made a difference in this fantastic event. If you would like more information on the *Benefit for Life* or would like to purchase a DVD of the concert, please email Amy Dotson at Dotson@hartford.edu.



SAI recital chair Amy Dotson with niece, Cassie Southwick, the inspiration for the concert.



9 year-old composer and pianist, Thomas Ice

FREQUENTLY ASKED QUESTIONS....

Answered by Dr. Robert J. Shprintzen

The following are among the questions submitted in writing by registrants at the 11th Annual Meeting of the Foundation. We will continue to publish the answers in upcoming newsletters to all of the questions submitted at the meeting, so keep an eye out for your question.

Are teeth affected by VCFS? Does this condition make children more prone to having bad teeth with their second set whether or not good dental care is given?

The primary teeth (baby teeth) are often quite soft in VCFS with thin enamel in early childhood resulting in rotting and multiple caries (cavities). Of course, there are other issues that can make the situation worse, such as reflux, water that is not fluoridated, diet, taking a bottle to bed at night (causing decay called milk-bottle caries), and medications. However, many children with VCFS do have many caries and rotting primary teeth in childhood in spite of good dental care, fluoride, and absence of reflux. It may be hypothesized that this relates somehow to calcium metabolism, but there is no hard evidence to support this right now. Other factors may be in operation. The good news is that in most cases, the permanent teeth are not usually as badly affected. It should be pointed out that if there are problems with immune disorders and congenital heart disease, one needs to be careful about controlling bacteria in the mouth, so it is important to make sure that proper dental care is provided and that proper precautions be taken to prevent infection if there is a history of congenital heart anomalies.

.I am a speech pathologist seeing a 5 year with VCFS. He has some immunology issues with lower T-Cell count. His immunologist adamantly says we can't take out the tonsils before pharyngeal flap surgery because he needs all the t cells he can get. The child is severely hypernasal. Is there anything to suggest that tonsillectomy would really make things worse for VCFS kids?

This immunologist is not correct. First of all, by age 5, the tonsils are doing very little in terms of T cells. There has been published research to show that tonsillectomy has no effect on the immune system. A recent study in *The International Journal of Pediatric Otorhinolaryngology*, one of the top tier medical journals, showed that humoral and cellular immune response decreases immediately after tonsillectomy but comes back to normal later. The reason for this is that when the tonsils are present and chronically irritated, they increase white cell production. When the

tonsils are removed, the stimulus for white cell production disappears so the white cells drop a bit. However, most importantly, immune function does not change. In some cases, the illness pattern improves because the airway opens up and reduces episodes of upper airway and lower airway illness. The tonsils are only a very, very small part of the immune system and the body has many other ways to fight infections and produce white blood cells. Also, doing a pharyngeal flap with tonsils can cause major complications from obstructive sleep apnea, a potentially dangerous complication. Furthermore, the literature is quite clear on the issue of low T-cell counts in VCFS....it is not so much the count as the function and types of T cells. The history of illnesses is probably the best guide. However, the research is clear on the risk that tonsils create when pharyngeal flap is being considered whereas the evidence is quite clear that tonsillectomy does not impair immune response.

We had our 6 month follow-up with the cardiologist today. Our son still has a medium sized ASD and he has a cleft palate. The Cardiologist is sending us to a surgeon who specializes in Cleft repair. My first question is when is the optimum time to have palate surgery? The first plastic surgeon we consulted wants to wait until he is 18 - 24 months of age. Is that wise? Is there a higher risk of infection? What is the preferred cleft repair method in children with VCFS?

There is only one reason for palate repair.....speech. Because speech normally begins with first word at 12 months or so, we usually recommend 9 - 12 months. However, in your son's case, because there is likely to be a mild delay, there may not be a problem with waiting until 12 - 18 months if there is a health or cardiac concern. Of course, this cannot be determined without an examination of your son. Most people agree that 18 - 24 months is too late. However, one caution is that very few children with VCFS develop normal speech after primary palate repair, and a second operation, usually pharyngeal flap, is almost always necessary after 4 years of age. In terms of the type of repair, that depends on the surgeon and the width of the cleft. It is important to ask surgeons about their experience and their outcomes.

DONATIONS

The VCFS Educational Foundation relies on dues and contributions to fulfill its mission to disseminate educational information about the syndrome. We gratefully acknowledge the following individuals for their donations, which were made since our last newsletter.

The total in gifts received from January through April 2005 was \$10,507. Thank you to all of our generous donors and to those who solicited their support.

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MEMBERSHIP UPDATE

The VCFS Educational Foundation welcomed 135 new members in 2005.

ANNUAL MEETING

VCFS Down Under - November 2-4, 2006

The Educational Foundation is, in partnership with the VCFS Foundation of Queensland (Australia) holding its 13th Annual Scientific Meeting in Brisbane, Australia, from Thursday 2 November through Saturday, 4 November, 2006. The planning for the meeting is well advanced. A Liaison Committee, formed in Atlanta, has been meeting (approximately) monthly, for some time. A Professional Program Committee (led by Dr. Karen Golding-Kushner and Dr. Bob Shprintzen) is in place. We have been fortunate in attracting several respected medical professionals from outside Queensland, to ensure that we maximise the professional participation in and attendance at "VCFS Down Under" in November this year. In particular, Professor Agnes Bankier, a geneticist and director of the Genetic Health Services of Victoria (and formerly of the Royal Children's Hospital in Melbourne) has joined the Professional Program Committee; as have Doctor Belinda Barton and Ms Suzi Drevesek, from the Children's Hospital at Westmead, Sydney and the University of Sydney, respectively. We are looking forward to working with these dedicated Australian professionals to stage a wonderful meeting in Brisbane in November.

The format for the conference will follow the tradition of VCFS Educational Foundation meetings. The program will combine papers reporting on the latest medical and scientific research developments, papers giving a more familiar run through of the more common features of VCFS, and tried and proven techniques to manage those problems; with breakout discussion sessions and the ever popular Question and Answer sessions with experts who volunteer their time for this purpose.

Preliminary details for this very exciting meeting are on the websites of both the Educational Foundation (www.vcfsef.org) and the VCFS Foundation of Queensland (www.vcfs.com.au). The local arrangements are also very well advanced. The meeting will be held at the Carlton Crest Hotel, Roma Street, Brisbane. For those travelling from overseas, the VCFS Foundation of Queensland has engaged a travel agent (Mrs Mandy Dwyer of Travelworld Main Beach, email mandy@mainbeachtravel.com.au).

The Liaison Committee is planning to publish a Call for Abstracts on both websites (and with some direct invitations) before this newsletter goes to print. The local committee in Brisbane, Australia are delighted by the prospect of welcoming a large number of Educational Foundation members to Brisbane in November. One promise we know we can make - you'll have a simply wonderful time. See ya there mate!

2006 VCFSEF Conference in Strasbourg

The next international VCFSEF conference will be held July 7, 8 and 9, 2006 in the beautiful city of Strasbourg. Strasbourg is a city rooted in tradition, where its art, architecture and history make it one of France's "must-see" visitor destinations. The Rhine River encircles the medieval city center where visitors can admire the awe-inspiring cathedral, picturesque timber-facade houses and quaint shops. Relying heavily on its local products, Strasbourg's regional cuisine and wine are world renowned and can be enjoyed in the city's traditional restaurants as well as in its local "winstubs." Strasbourg therefore promises to be a lovely setting for next year's conference. The conference presentations will be held in the European Pole of Economy building which is fully-equipped for any audio-visual requirements, including simultaneous translation services that will be offered in both French and English. Reduced rates for accommodations in Strasbourg are currently being researched. A portion of the conference costs will be paid for with the assistance of local subsidies. Further details regarding conference registration will be available in the coming months. In the meantime, please save the date! For more information, you may contact Dominique Pfeiffer, president of the French association GENERATION 22, at dom.pfeiffer@wanadoo.fr

STRASBOURG PROGRAM

12th Annual International Scientific Meeting July 7 - 9, 2006, Strasbourg, France

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.
Hosted by Génération 22 and the VCFSEF European Network

Friday Morning, 7 July 2006

- 9:00 – 9:20: Opening Ceremonies and Introductions
Dominique Pfeiffer, Présidente, Génération 22, Strasbourg, France
Stephen Russell, B.A. LL.B, President, VCFSEF
Karen J. Golding-Kushner, Ph.D., Executive Director, VCFSEF
- 9:20 – 9:35: Keynote Address: Jean-Louis Mandel, Professeur au College de France, Directeur de L'IGBMC, Strasbourg, France
- 9:35 – 9:45: A Brief History of VCFS and the Educational Foundation; *Robert J. Shprintzen, Ph.D., Upstate Medical University, Syracuse, NY, USA*
- 9:45 – 10:20: Panel: The European Network of the VCFS Educational Foundation
- 10:20 – 10:45: Recognizing the 22q11 deletion syndrome; *Solveig Oskarsdottir, Göteborg, Sweden*
- 10:45 – 11:05: Clinical findings in neonates with VCFS; *M. Cristina DiGilio, M.D., Ospedale Bambino Gesù, Roma, Italia*
- 11:05 – 11:15: Questions and Discussion
- 11:15 – 11:30: Refreshment Break
- 11:30 – 11:50: Cardiac surgery results in patients with conotruncal heart defects: impact of VCFS; *Bruno Marino, M.D., Ospedale Bambino Gesù, Roma, Italia*
- 11:50 – 12:05: Feeding and weight gain in VCFS: comparisons to normal growth curve is a mistake; *Anne Marie Higgins, R.N., F.N.P., Robert J. Shprintzen, Ph.D., Upstate Medical University, Syracuse, NY, USA*
- 12:05 – 12:30: Panel Discussion and Questions: phenotype to genotype correlation in VCFS and its potential importance to management; *Yves Alembik, Moderator; Nicole Philip, Pierre Sarda, M. Cristina DiGilio*
- 12:30 – 1:45: Lunch with the Experts

Friday afternoon

- 1:45 – 2:00: Phonological approach to speech and language therapy for young children with VCFS; *Virginia L. Dixon-Wood, M.A., University of Florida, Gainesville, FL, USA*

STRASBOURG PROGRAM...

- 2:00 – 2:15: Phonica faces: a tool for providing speech therapy in patients with VCFS; *Antonio Ysunza, M.D., Hospital Gea Gonzales, Mexico City, Mexico*
- 2:15 – 2:30: Application of the sound, shape, and color (SSC) principles for treating VCFS speech disorders; *Ariela Nachmany, Ph.D., Sapir Medical Centre, Kfar Saba, Israel*
- 2:30 – 3:00: Approaches to speech intervention in VCFS: general principles, special “tricks,” and matching techniques to disorders; *Karen J. Golding Kushner, Ph.D., Executive Director, VCFSEF, Private Practice in Speech-Language Pathology, East Brunswick, NJ, USA*
- 3:00 – 3:15: Questions and Discussion
- 3:15 – 3:30: Refreshment Break
- 3:30 – 3:45: Velopharyngeal insufficiency in 22q11.2 deletion syndrome: speech results after surgery; *Nathalie Degardin-Capon, Marie Arnoldi, Sylvie Lejeune, Salima Mahammed, Véronique Martinot-Duquennoy, Philippe Pellerin, Children University Hospital of Lille, France*
- 3:45 – 4:05: Pharyngeal flap surgery in VCFS: outcomes and long-term follow-up in a large sample by a single surgeon. *Sherard A. Tatum III, Upstate Medical University, Syracuse, NY USA*
- 4:05 – 4:30: Panel Discussion: Speech diagnosis, speech therapy, and surgical management; *Sherard A. Tatum, III, M.D., Syracuse, NY, USA; Partice Oger; Noel Garabedian; Judith Hohlfeld; Philippe Pellerin, Karen Golding-Kushner, Ph.D.*
- 4:30 – 4:40: 3D Models of Face Shape in Velo-cardio-facial Syndrome; *Peter Hammond, Judith Allanson, Linda Campbell, Raoul Hennekam, Tim Hutton, Kieran Murphy, Katrina Prescott, Pete Scambler, University College of London, London, UK*
- 4:40 – 4:50: Micro délétion et santé bucco-dentaire: à partir d’une étude clinique; *N. Marchetti, R. Lalonde, D. Droz-Desprez, M. Simonin, C. Strazielle, Nancy, France.*
- 4:50 – 5:00: Micro délétion et santé bucco-dentaire: à partir d’une étude clinique; *Dominique Droz-Desprez, N. Marchetti, N. Beltramo, C. Strazielle, Nancy, France.*
- 5:00 – 5:10: A report from the VCFSEF on recommended diagnostic and treatment protocols
- 5:10 – 5:30: Panel discussion, questions, and comments on the recommendations
- 5:30 – 5:40: VCFSEF Meeting in Australia; *Stephen Russell, Brisbane, Australia*
- 5:45 – 6:30: Annual Business Meeting, VCFSEF

Saturday Morning, 8 July 2006

- 9:00 – 9:25: Genetic modifiers and genetic susceptibility in VCFS; *Bernice Morrow, Ph.D., Albert Einstein College of Medicine, Bronx, NY, USA*

STRASBOURG PROGRAM...

- 9:25 – 9:35: Is hyperprolinemia associated with cognitive and/or psychotic symptoms in VCFS patients? An association study; *Dominique Campion, Faculté de Médecine, Rouen, France; E. Bumsel, B. Hecketsweiler, N. Drouin-Garreau, S. Legallic, G. Opolczynski, Th. Frébourg (Rouen); S. Manouvrier-Hanu, C. Fantini (Lille); Th. Van Amelsvoort (Amsterdam); A. Swillen, A. Vogels (Leuven); A. Philippe, D. Heron (Paris); N. Philip, M. Carlier, A. Gerard (Marseille), P. Sarda (Montpellier); Y. Alembik, M. Lacambre (Strasbourg); D. Lacombe (Bordeaux); O. Boespflug-Tanguy (Clermont-Ferrand).*
- 9:35 – 9:50: The challenges of matching the genetic deletion to the clinical expression in VCFS; *Robert J. Shprintzen, Ph.D., Upstate Medical University, Syracuse, NY, USA*
- 9:50 – 10:05: Questions and Discussion
- 10:05 – 10:25: Behaviors and emotions from childhood to adulthood: implications for psychological treatment in VCFS; *Stephan Eliez, M.D., University of Geneva, Geneva, Switzerland*
- 10:25 – 10:45: Risk factors and developmental trajectories in VCFS; *Doron Gothelf, M.D., Schneider Children's Medical Center, Petah Tiqva, Israel; Stanford University, Stanford, CA, USA*
- 10:45 – 11:00: Questions and Discussion
- 11:00 – 11:15: Refreshment break
- 11:15 – 11:35: Development and behaviour in VCFS; *Ann Swillen, Ph.D., Leuven, Belgium*
- 11:35 – 11:55: Multiple related impairments in cognitive processing of objects and space in VCFS; *Tony Simon, Ph.D., University of California, Davis, Sacramento, CA, USA*
- 11:55 – 12:15: Neuropsychiatric and behavioural problems in 100 individuals with 22q11 deletion syndrome; *Lena Niklasson, Peder Rasmussen, Sólveig Óskarsdóttir, Christopher Gillberg, Göteborg University, Göteborg, Sweden*
- 12:15 – 12:30: Questions and Discussion
- 12:30 – 1:30: Lunch with the Experts
- Saturday afternoon**
- 1:30 – 1:40: Carole Bouquet, French film star, will address the meeting.
- 1:40 – 1:50: Living with VCFS in the 21st Century; *Raymond Tanner, Adelaide, Australia*
- 1:50 – 2:05: Paths to Success; *Alexandra Oppenheimer, M.Ed., Mamaroneck, NY, USA; Suzi Oppenheimer, New York State Senator, Mamroneck, NY, USA.*
- 2:05 – 2:10: A personal story from France.
- 2:10 – 2:30: Emotional Processing in Children and Adolescents with VCFS: Cognitive and Neural Correlates; *Wendy Kates, Ph.D., Upstate Medical University, Syracuse, NY, USA*

STRASBOURG PROGRAM...

- 2:30 – 2:40: Social Cognition: In the Eye of the Beholder; *Ryan Murray, Martin Debbané, Bronwyn Glaser, Stephan Eliez, Geneva, Switzerland*
- 2:40 – 3:00: Brain connectivity differences in VCFS that might explain cognitive dysfunctions; *Tony Simon, Ph.D., University of California, Davis, Sacramento, CA, USA*
- 3:00 – 3:15: Questions and discussion
- 3:15 – 3:35: Structural Imaging of the Brain in VCFS; *David Skuse, Institute of Child Health, London, UK.*
- 3:35 – 3:45: Abnormal cortical folding in the brain of patients with VCFS; *Marie Schaer, Bronwyn Glaser, Stephan Eliez, M.D., University of Geneva, Geneva Switzerland*
- 3:45 – 3:55: Questions and Discussion
- 3:55 – 4:10: Refreshment Break
- 4:10 – 4:30: Dopaminergic neurotransmission in VCFS before and after dopamine depletion; *Therese van Amelsvoort, M.D., Ph.D., University of Amsterdam, Amsterdam, The Netherlands*
- 4:30 – 4:50: FISHing for the neurobiology of behaviour in VCFS; *Kieran Murphy, M.D., Royal College of Surgeons, Dublin, Ireland.*
- 4:50 – 5:10: Association of the low activity COMT allele with ADD/ADHD and obsessive compulsive disorder in VCFS; *Merav Burg, Elena Michaelovsky, Amos Frisch, Abraham Weizman, Alan Apter, Doron Gothelf, Schneider Children's Medical Center of Israel, Petah Tiqva, Israel.*
- 5:10 – 5:20: What can face processing tell us about cognitive and social development in VCFS? *Bronwyn Glaser, Martin Debbané, Marie Schaer, Sandra Martinez, Lea Matasci, and Stephan Eliez, Geneva, Switzerland*
- 5:20 – 5:30: Questions and Discussion
- 5:30: Parents meeting: Génération 22.

Sunday Morning, 9 July 2006

- 9:00 – 9:15: To recognize or to recollect? Memory processes at work in VCFS; *Martin Debbané, Bronwyn Glaser, Marie Schaer, Stephan Eliez, University of Geneva, Geneva, Switzerland*
- 9:15 – 9:35: Mathematical disabilities in children with Velo-Cardio-Facial Syndrome; *B. De Smedt, A. Swillen, K. Devriendt, J-P Fryns, L. Verschaffel, P. Ghesquière, Leuven, Belgium*
- 9:35 – 9:45: Surdit  congenitale et deletion 22q11: une deletion peut en cacher une autre. *Catherine Blanchet, F. Venail, P. Blanchet, P. Sarda, A.P. Roux, M. Claustre, A. Uziel, M. Mondain, Montpellier, France*

STRASBOURG PROGRAM...

9:45 – 10:00: Hearing disorders in VCFS

10:00 – 10:30: Educational interventions for children with VCFS; *Donna Cutler-Landsman, Madison, WI, USA*

10:30 – 10:45: Questions and Discussion

10:45 – 11:05: Refreshment Break

11:05 – 11:20: Leg Pains in VCFS; *Ahmad Al-Khattat, M.B.B.Ch., Northampton, U.K.*

11:20 – 11:35: Motor development in children with VCFS, part 1, *Katrijn Van Aken, Ann Swillen, Hilde Feys, Tamara Adriaens, Loes Nelissen, Luc Martens, Marc Gewillig, Koen Devriendt, Jean-Pierre Fryns, Leuven, University Hospital Gasthuisberg, Belgium*

11:35 – 11:50: Motor development in children with VCFS, part 2; *Katrijn Van Aken, Ann Swillen, Marc Gewillig, Koen Devriendt, Annelies Van Role, Johan Simons, Jean-Pierre Fryns, University Hospital Gasthuisberg, Belgium*

11:50 – 12:00: Questions and Discussion

12:00 – Conclusion: Closing comments

Poster Sessions:

Social skills, executive function, and obsessional behavior in VCFS; *Arild Berglund, Sissel Iversen, Stavanger University Hospital, Stavanger, Norway*

Cognition and brain in children with VCFS; *L.E. Campbell, A.F. Stevens, R. Azuma, R.G. Morris, D.G.M. Murphy, K.C. Murphy, University of Newcastle, Newcastle, Australia; King's College, London, U.K.; Royal College of Surgeons, Dublin, Ireland*

Latéralité et cognition chez des personnes porteuses de maladies génétiques: Comparaison de personnes porteuses du Syndrome de DiGeorge et du Syndrome de Williams-Beuren. Résultats préliminaires; *Aude Gérard-Desplanches (Provence, France), Christine Deruelle (Marseille, France), Silvia Stefanini (Parma, Italy), Nicole Philip (Marseille, France), Virginia Volterra (Rome, Italy), Stefano Vicari (Rome, Italy), Gene Fisch (New York, USA), Michèle Carlier (Provence, France)*

Glottal articulation, obturator and communication; *Bjørg Solfrid Lia, TAKO Center, Oslo, Norway*

La reconnaissance des visages chez les personnes atteintes du syndrome vélo-cardio-facial; *Sandra Martinez, Bronwyn Glaser, Martin Debbané, Stephan Eliez, Geneva, Switzerland*

Summer camping experience with children and adolescents with VCFS at Victory Junction in Randleman, NC; *Paula Goldenberg, M.D., M.S.W., Duke University Medical Center, Durham, NC, USA*

STRASBOURG PROGRAM...

Poster Presentations, Clinic Descriptions

Traitement et mémoire visuo-spatiale chez les individus atteints du syndrome vélo-cardio-facial : une investigation au travers du Test de rétention visuelle de Benton. *Lea Matasci, Bronwyn Glaser, Martin Debbané, Sandra Martinez, Stephan Eliez, Geneva, Switzerland*

The Stockholm 22q11 Deletion Syndrome Team – a presentation and a report from a parent questionnaire on speech and language, VPI, and oral motor development; *Liisi Raud Westburg, Mc.S., Gunilla Hinningsson, Ph.D.*

Project for the Formulation of a diagnostic and therapeutic protocol; *Giuletta Angelelli Cafiero, Caterina Cancrini, Rome, Italy*

Presentation du laboratoire de neuroscience et neuroimagerie, Geneva, Switzerland. *Martin Debbané, Stephan Eliez, Bronwyn Glaser, Marie Schaer, Sandra Martinez, Ryan Murray, Léa Matasci*

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2007

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