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# VCFSEF Newsletter

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Voice of the VCFS Educational Foundation

Spring - May 15, 1999

University Hospital, 750 E. Adams St , Jacobsen Hall Room 707, Syracuse, NY 13210 - Telephone:(315)464-6590

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## 1999 Annual Conference in Milwaukee this July!!!

The 5<sup>th</sup> Annual Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation will be held at Children's Hospital in Milwaukee, WI, Boston, MA, July 16-18, 1999. The preliminary agenda is on page 2. The agenda is subject to minor changes before the conference. Individuals who are preregistered will receive final agenda and information approximately two weeks before the conference.

Lodging is still available at the **Midway Hotel**, \$69.00 per night. **The Midway** is approximately 3 miles from the meeting hall, but Susan Marks, local activities chairperson, is attempting to arrange shuttle service to and from. Contact the hotel directly at (414) 774-3600 to arrange for a room; mention reservation code #071699CH, which is the VCFS Meeting at Children's Hospital. If you prefer luxury accommodations, try **The Pfister Hotel** in downtown Milwaukee at (800) 558-8222. Lastly, dorm rooms are available at **Sargent Hall of Wisconsin Lutheran College** -- one block from the meeting hall -- for \$25.00 per person. They accommodate up to 4 people; doubles and singles are available. Contact **Susan Marks** by mail at: Children's Hospital of Wisconsin, P.O. Box 1997, Milwaukee, WI 53207. A dormitory reservation form is available in this issue of the newsletter. ❖

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## Annual Membership Dues

Our last newsletter fell around Christmas and I'm afraid our Call for Dues got lost in some of those piles of holiday wrapping paper that got tossed out. Your annual dues finance production and distribution of the periodic newsletter(s) and other educational information, and helps finance the annual conference. From a membership of a little over 1000 households, a very small percentage have responded. Membership dues are as follows:

- Single Membership: \$25.00
- Family Membership: \$30.00
- STUDENT Membership: \$10.00
- Your OPTIONAL contribution(s) of \$5.00 or more to the Caitlin Lynch Memorial Fund helps pay registration fees for some individuals who could not otherwise afford to attend the annual conference.
- Your OPTIONAL contribution(s) of \$5.00 or more to the Lipson Memorial Fund helps defray expenses of an individual who travels from Australia to attend the annual conference.

**Note:** Deduct \$5.00 if you pay your annual dues AND register for the conference at the same time. For your convenience, we have included a dues and membership form in this issue. Thank you for your support. ❖

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## New Support Group

A new support group in Cincinnati -- The Ohio Valley / Tri-State VCFS Support Group -- is headed by Ms. Teresa Paul (lovingly referred to as "Mother-Teresa"). The group serves Ohio, Indiana and Kentucky, and the Ohio Valley, which also includes states a little further away.

In addition to the normal VCFS support issues, the group is focusing intensely on public awareness and resources for VCFS and other special kids. For more information contact Ms. Teresa Paul, 9327 Bluewing Terrace, Cincinnati, Ohio 45236, (513) 793-375 or email her at "mothertp@aol.com". ❖

### Conference Agenda (Preliminary)

This is the Preliminary Program for the Conference in Milwaukee. There may still be some last minute changes. Conference pre-registrees will receive the final agenda and information approximately two weeks before the conference. ❖

#### Friday, July 16, 1999

- Noon - 12:30 Registration  
 12:30 - 12:45 Welcoming remarks, Donna Landsman, President; Susan Marks, Local Arrangements Chair; Robert J. Shprintzen, Executive Director.  
 12:45 - 1:15 Update: The data base. What are the most common problems in VCFS? Robert J. Shprintzen, Executive Director.  
 1:15 - 1:45 Cardiac issues in VCFS. Stuart Berger, M.D., Children's Hospital of Wisconsin, Milwaukee.  
 1:45 - 2:05 Questions and Discussion  
 2:05 - 2:25 Coffee Break  
 2:25 - 3:00 A candidate gene for the major findings in VCFS. Deepak Srivastava, M.D., University of Texas Southwestern Medical Center at Dallas  
 3:00 - 3:30 Molecular genetics and VCFS: Are we closer to understanding the problem? Bernice Morrow, Ph.D., Albert Einstein College of Medicine, Bronx, NY.  
 3:30 - 3:50 Questions and Discussion  
 3:50 - 4:20 Parenting perspectives: encouragement for the road. Susan E. Busch, M.S.N., N.P.  
 4:20 - 4:30 The Role of the Support Group: A Global Perspective. Julie Squair, the 22q11 Group, United Kingdom  
 4:30 - 4:40 My son is Perfect, Whole, and complete. Deborah Gray, Kentfield, CA.  
 4:40 - 5:00 Fast Forward: An Introduction. Susan Oliff-Carneol, M.S., Milwaukee  
 5:00 - 6:00 Business Meeting.

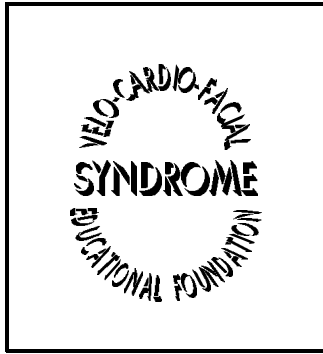
#### Saturday, July 17, 1999

- 9:00 - 10:30 Psychiatric issues in VCFS: A debate and interchange. Anne Bassett, M.D., University of Toronto; Kieran Murphy, M.D., University of Cardiff, Wales, United Kingdom; Demetri Papolos, M.D., Albert Einstein College of Medicine, Bronx, NY.  
 10:30 - 11:00 Questions and Discussion  
 11:00 - 11:15 Coffee  
 11:15 - 12:00 Improving social communication, self esteem, and coping skills: A child and parent group intervention model. Jim Ellis, M.S.W.; Tami Gumz, M.S.; Susan Marks, M.S.; LuAnn Weik, M.S., Children's Hospital of Wisconsin, Milwaukee.  
 12:00 - 12:20 Questions and Discussion  
 12:20 - 1:45 Lunch  
 1:45 - 2:00 Why do kids with VCFS regurgitate through the nose, and is it dangerous? Some insights into feeding problems. Anne Marie Higgins, N.P., S.U.N.Y. Health Science Center at Syracuse, Syracuse, NY.  
 2:00 - 3:00 To Tube or Not to Tube. Robert Beecher, M.S.; Ellen Blank, M.D.; Midge Kirby, M.S., R.D.; Children's Hospital of Wisconsin, Milwaukee.  
 3:00 - 3:20 Questions and Discussion.  
 3:20 - 3:40 Coffee  
 3:40 - 4:00 Leg pains and VCFS: The latest news. Ahmad Al-Khattat, Northampton, United Kingdom.  
 4:00 - 4:50 What can structural and functional MRI tell us about VCFS? Stephan Eliez, M.D.; Christopher D. White, B.A.; Eric J. Schmitt, B.S.; Vinod Menon, Ph.D.; Allan L Reiss, M.D., Stanford University School of Medicine, Stanford, CA.  
 4:50 - 5:05 Neuropsychological profile of children with VCFS. Carrie E. Bearden, Edward Moss, Michael Woodin, Paul Wang, Donna McDonald-McGinn, Elaine Zackai, Children's Seashore House, Philadelphia, PA.  
 5:05 - 5:20 Questions and Discussion

#### Sunday, July 18

- 9:00 - 10:00 The nitty-gritty of speech therapy for kids with VCFS. What works, what doesn't work, and how to do it. Karen J. Golding-Kushner, Ph.D., East Brunswick, NJ.  
 10:00 - 10:20 Velopharyngeal insufficiency and abnormal articulation disorders: what is the relationship? Natalie Havkin, M.S., S.U.N.Y. Health Science Center at Syracuse, Syracuse, NY.  
 10:20 - 10:50 Questions and Discussion.  
 10:50 - 11:10 Coffee  
 11:10 - 12:00 Planning for the future of your special needs child. Nadine O. Vogel, M.B.A., SNAP (Special Needs Advocate for Parents), Los Angeles, CA.  
 12:00 - [ ] Leg pain clinic. Ahmad Al-Khattat, Stuart Goldman

**Conference Scholarships:** The Lynch Memorial fund is providing a limited number of scholarships for the conference, to cover registration and the Friday night dinner. Interested individuals should send a letter to the Foundation requesting consideration. ❖



**Velo-Cardio-Facial Syndrome Educational Foundation**

**Officers:**

*Executive Director:*  
Robert J. Shprintzen  
(Syracuse, NY)  
*President:*  
Donna L. Landsman  
(Madison, WI)  
*Secretary-Treasurer*  
Lisa Jennings (Boston, MA)

*Board of Directors*  
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Barbara Dandron (Ft. Lauderdale, FL)  
Pamela Hunter (Cupertino, CA)  
Raju Kucherlapati (Bronx, NY)  
Jeff Landsman (Madison, WI)  
Susan Marks (Milwaukee, WI)  
*Liaison Chairperson:* Linda Walters (Toronto, Ont, Canada)

*Editor:* Deborah Hung Copenheaver (Washington, D.C.)

**DUES NOTICE**

As approved unanimously by the full membership of The Foundation, voluntary dues have been assessed according to the schedule of suggested minimums listed below:

Single Membership .....	\$25.00
Family Membership which includes immediate family (spouses, children) .....	\$30.00
Student Membership .....	\$10.00

We also urge pledges of \$5 for the Caitlin Lynch Memorial Fund, to provide scholarships for our annual meeting, and \$5 to the Tony Lipson Memorial Fund, to allow a member from Australia to attend our annual meeting. Please make your checks payable to The Velo-Cardio-Facial Syndrome Educational Foundation. Your payment is tax deductible, as are any additional donations you might wish to make. In cases of hardship, The Foundation will grant membership without the collection of dues. In such cases, The Foundation will waive dues, if the appropriate box is checked below and returned to us. Dues, or requests for waivers, must be received no later than January 31, 1999 in order to maintain membership, remain on the Foundation's mailing list, and to assure delivery of the next periodic newsletter. Your canceled check will be your receipt unless otherwise requested. Thank you for helping to fulfill the mission of The Foundation.

Robert J. Shprintzen, Ph.D.  
Executive Director

Donna L. Landsman  
President

Lisa Jennings  
Secretary-Treasurer

My membership category is:     Individual     Family     Student     Professional

For family dues, please list additional family members: \_\_\_\_\_

Enclosed is my check or money order for \$ \_\_\_\_\_ for my 1999 dues, plus:

- \$5 for the Caitlin Lynch Memorial Fund (*optional*)
- \$5 for the Tony Lipson Memorial Fund (*optional*)

Total enclosed: \$ \_\_\_\_\_

Waiver:

- I request a waiver of my dues. Please retain me as a member of the Foundation.

**\*\* Please fully complete information on the other side of this form...**

# Membership Application / Renewal Form

## The Velo-Cardio-Facial Syndrome Educational Foundation

Name: \_\_\_\_\_  
first                      middle initial                      last

Address: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_

*please include area code and extensions; if not in U.S./Canada, include country & city code*

Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ Work Hours: \_\_\_\_\_  
month                      day                      year

What is your interest in velo-cardio-facial syndrome? \_\_\_\_\_ I have velo-cardio-facial syndrome

- I am the parent of someone with velo-cardio-facial syndrome (if so, please provide name, date of birth, and sex of your child) \_\_\_\_\_
- I am a student or resident interested in learning more about velo-cardio-facial syndrome
- Other (please explain): \_\_\_\_\_
- I am a professional/health care provider working with individuals with velo-cardio-facial syndrome  
*If you are a professional or health care provider interested in joining, what is your professional field?* \_\_\_\_\_ *Degree(s):* \_\_\_\_\_ *Certified or licensed?* yes \_\_\_ no \_\_\_

How did you find out about the Foundation? \_\_\_\_\_

Send this completed form to: Dr. Robert J. Shprintzen  
 Communication Disorder Unit, Jacobsen 707  
 Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome  
 SUNY Health Science Center at Syracuse  
 750 East Adams Street  
 Syracuse, NY 13210

Or Fax to: 315-464-5321 or email data to vcfsef@hscsyr.edu  
 Telephone: 315-464-6590

### AUTHORIZATION TO RELEASE INFORMATION

I authorize the Educational Foundation to release my name, telephone number, or email address to other members and to publish it in a directory. The purpose for this permission is to connect people in localities so that support can be offered and information distributed. We will not distribute, sell, or release this information for commercial purposes, or for the enhancement of individual doctors or hospitals.

You may release my:  Name     Address     Phone #     Email address     Release NONE

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

New Membership     Renewal Membership     Note change of address

**Dormitory Reservation Form**

Fifth Annual Meeting  
 Velo-Cardio-Facial Syndrome Educational Foundation  
 Children's Hospital of Wisconsin, Milwaukee, WI  
 July 16 - 18, 1999

First, Middle, Last Name:

Address:

City, State, Zip/Province

Home Phone\*\*:

Work Phone\*\*:

Fax:

Email:

**The following reservations are requested. Thank you.**

Arrival Date/Time:

# of Nights Needed:

# People in Group

- Dormitory lodging is \$25.00 per person.
- You may be sharing a room with up to three other individuals.
- List names of all persons traveling in your group below:

\_\_\_\_\_ Male / Female (circle one) [form submitter]

\_\_\_\_\_ Male / Female (circle one)

\_\_\_\_\_ Male / Female (circle one)

\_\_\_\_\_ Male / Female (circle one)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Mail completed form to:**  
 Susan Marks  
 Children's Hospital of Wisconsin  
 P.O. Box 1997  
 Milwaukee, WI 53207

**DORM FEES WILL BE COLLECTED AT THE CONFERENCE**

**PREREGISTRATION FORM  
Fifth Annual Conference  
The Velo-Cardio-Facial Syndrome Educational Foundation  
July 16 - 18, 1999 - Children's Hospital of Wisconsin, Milwaukee, WI**

Name: \_\_\_\_\_  
*first*
*middle initial*
*last*

Address: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_  
*( please include area code and extensions; if not in U.S./Canada, include country & city code)*

Fax: \_\_\_\_\_ E-mail: \_\_\_\_\_

I am a member of the Foundation: yes \_\_\_\_\_ no \_\_\_\_\_ Lay \_\_\_\_\_ Professional \_\_\_\_\_  
*If you are not a member, contact us for a membership form, send it with the preregistration, you will receive the member's registration fee*

**Accommodations (see enclosed announcement):** As in years past, there are several levels of accommodations available. Dormitory rooms at Sargent Hall of Wisconsin Lutheran College, one block from the meeting hall, will be available for \$25 per person. Rooms can accommodate up to 4 people, and both doubles and singles are available. To book dormitory rooms, contact Susan Marks by mail at: Children's Hospital of Wisconsin, P.O. Box 1997, Milwaukee, WI 53207. The main hotel for the meeting will be the Midway Hotel which is 3 miles from the meeting hall. Shuttle service to and from the hotel will be available. Rates are \$69 per room. Contact the hotel directly at 414-774-3600 and mention that the reservation is for the VCFS Meeting at Children's Hospital, code # 071699CH. If you prefer luxury accommodations, try the Pfister Hotel in downtown Milwaukee at 800-558-8222.

**Registration Fees:** *Enclose check or money order. For registrations from outside of the United States, please send a bank draft payable in U.S. dollars*

Single preregistration, member . . . . .	\$40.00 U.S. _____
Family preregistration, 2 members (please list names below) . . . . .	\$60.00 U.S. _____
Single preregistration, nonmember: . . . . .	\$50.00 U.S. _____
Family preregistration, 2 nonmembers (please list names below) . . . . .	\$80.00 U.S. _____
Family preregistration, 3 or more members (please list names below) . . . . .	\$80.00 U.S. _____
Family preregistration, 3 or more nonmembers (please list names below) . . . . .	\$100.00 U.S. _____
Student member preregistration: . . . . .	\$30.00 U.S. _____
Student nonmember preregistration: . . . . .	\$40.00 U.S. _____
Optional Friday Night Southwestern Buffet Dinner: . . . . .	\$25.00 per person _____

**Total Enclosed:** \_\_\_\_\_

*\*\* For family registrations, please list all family members to be registered on reverse. Note: Registration fee at the door will be an additional \$10.00 per person, if space is available.*

- I am interested in a clinic on leg pains \_\_\_\_\_
- I am interested in a teen/young adult get-together \_\_\_\_\_

**Send completed form with check payable to: Velo-Cardio-Facial Syndrome Educational Foundation**

\_\_\_\_\_  
 Receipts will be available  
 at the door.  
 \_\_\_\_\_

c/o Dr. Robert J. Shprintzen  
 C.D.U., 707 Jacobsen Hall  
 SUNY Health Science Center at Syracuse  
 750 East Adams St., Syracuse, NY, 13210

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### STORY OF RAYMOND TANNER AND FAMILY (ADELAIDE - SOUTH AUSTRALIA)

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My name is Raymond Geoffrey Tanner. I was born on the 23 October 1949 in East Preston Melbourne Victoria Australia. I thought it was necessary to write about myself and my two sons. I hope this may give some other people with VCFS and their families some hope for the future.

James was my first son. He was born on October 21 1986, with VCFS, although we did not know it until my second son was diagnosed with the syndrome. James had a number of complications such as a hole in the heart, two aortas, cleft palate, and other deformities which are too sensitive to mention here. Unfortunately, James died at the age of 14 days old. The other unfortunate thing with James was that his outward appearance appeared to be normal, so he was not diagnosed at that time.

My second son, Andrew, was born on January 7 1988, and he had two holes in the heart, club feet, and a bifid uvula. He is now 11 years of age, and is currently having learning difficulties, speech problems, leg pains, and his mental age is a few years behind his chronological age. Although he has these problems, he has a great sense of humor, plays cricket, soccer and any sport with a ball in it.

I also have another child, a teenage daughter who is 14 years of age, and has not been diagnosed with VCFS.

I was diagnosed with the VCFS after my second son went to a genetics specialist at the Adelaide Women's and Childrens' Hospital. At the time, I was 38 years of age. My problems are caused by having a seventh nerve that does not function properly. This gave me an unusual facial expression. Those who are prejudice towards me refer to this likeness as being similar to a gorilla. In addition, I had a high bridged cleft palate at the time, which made my speech hard to understand. These problems had a major affect on my childhood and during my adult life.

In 1990 I had my cleft palate operated by the Head Surgeon of the South Australian Cranial Facial Unit, and my speech improved, although not 100 %. He also has done some minor operations on my face. While the changes are subtle, it did not stop some adults (and children)

making unnecessary comments. However, I have been able combat this prejudice, by admitting that they have a problem, and not me.

Although my life has been hard and my academic achievements during childhood were not great, my adult life has seen various achievements: the ability to be able to play the piano and electric organ, I graduated from University with a Bachelor of Management Degree, majoring in Operations and Logistics, and being married to a wonderful and supporting wife and mother of our two great children - - and of course having had James.

There is a lot more I could write about my childhood and adult life. However, I thought that my main message is, that there is hope at the end of the tunnel, and have trust and faith in those who try and keep you on track.

For those who would like to correspond and have someone to talk to about the experiences of personally having VCFS, my Email address is tanner@arcom.com.au. My address can be obtained from the VCFS Foundation.

Raymond Tanner & my family

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### Support Happening!

The VCFS/DI George Family Support Network of Washington would like to announce their Summer Family Fun camp, happening June 11th thru 13th. The event is fully sponsored by Camp Prime Time, and there is no charge for participation. For more information call Ms. Paula Shilby at (509) 672-2430, or write then at: POB 148 Yakima, WA. 98907-0148.

The Fun Camp hopes to bring families together from all over Washington state and is expected to be "an awesome experience", boat rides, fishing, roasting hot dogs and making s'mores for the kids and. . .sharing an open camp fire under the starry summer skies, for t he parents. ❖

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### www.vcfsef.org

It's official. The site is up and running and has replaced the previous web site of [www.hscsyr.edu/vcfsef](http://www.hscsyr.edu/vcfsef). The old site is still there, but only contains a link to the new location for those in. Web Hosting Service courtesy of *SurfXpress*, at <http://www.sxpress.com>. Look for new features and information in the future. ❖

### Recent VCFS Related Publications

Digilio MC, Marino B, Bagolan P, Giannotti A and Dallapiccola B. Microdeletion 22q11 and oesophageal atresia. Journal of Medical Genetics 1999 Feb;36(2):137-9.

Momma K, Matsuoka R and Takao A. Aortic arch anomalies associated with chromosome 22q11 deletion. Pediatric Cardiology 1999 Mar-Apr;20(2):97-102.

Tsai CH, Van Dyke DL and Feldman GL. Child with velocardiofacial syndrome and del (4)(q34.2): another critical region associated with a velocardiofacial syndrome-like phenotype. American Journal of Medical Genetics 1999 Feb 12;82(4):336-9.

Wakamiya M, Lindsay EA, Rivera-Perez JA, Baldini A and Behringer RR. Functional analysis of Gscl in the pathogenesis of the DiGeorge and velocardiofacial syndromes. Human Molecular Genetics 1998 Nov;7(12):1835-40.

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### Medical Transportation Options

The following organizations provide charity air medical transportation for needy people and their families. Some of our information is a little sketchy, but we provided the information below:

**Angel Flight NE**

800-549-9980

Contact: Kitty

Web Site: [www.angelflightne.org](http://www.angelflightne.org)**Angel Flight**

800-296-1217 (National Help Line)

Email: [angel-flightma@juno.com](mailto:angel-flightma@juno.com)Web Site: [www.angel-flight.org](http://www.angel-flight.org)**Air Lift**

800-446-1231

**Angel Plane**

(702) 261-0494

Contact: Bobbie Burnett

**Continental Airlines**

Contact: Mrs. Wolf

800-444-8414

**Mercy Medical**

Contact: Steve Patterson

(703) 361-1191

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### Velo-Cardio-Facial Syndrome Educational Foundation

Communication Disorder Unit

University Hospital

750 E. Adams Street - 708 Jacobsen Hall

Syracuse, NY 13210