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# VCFSEF Newsletter

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Voice of the VCFS Educational Foundation

November 1, 1999

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

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## 5th Annual Meeting in Milwaukee an Enormous Success !

The 5<sup>th</sup> Annual Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation was held in Milwaukee, July 16-18 at Children's Hospital of Wisconsin and the Medical College of Wisconsin. Attendance, as in past years, was approximately 200 with registrants from the U.S., Canada, England, Belgium, and Australia. The meeting was a perfect blend of science, social activities, and close contact between lay members and professional members of the Foundation.

The guest faculty included Stephan Eliez of Stanford University School of Medicine who presented his group's original research on advanced magnetic resonance imaging procedures in the study of individuals with velo-cardio-facial syndrome, and the application of functional MR to study the syndrome. Participating in a lively and informative panel discussion were three psychiatrists who have been researching VCFS, including Anne Bassett of the University of Toronto, Kieran Murphy of the University of Cardiff in Wales (recently moved to London and the Institute of Psychiatry at King's College), and Demitri Papolos of the Albert Einstein College of Medicine.

Molecular genetics was addressed by Deepak Srivastava of the University of Texas Southwestern Medical Center in Dallas, and Bernice Morrow of the Albert Einstein College of Medicine. Ahmad Al-Khattat from Northampton, England, soothed more than a few legs with his talk and leg pain clinic held

Natalie Havkin from the State University of New York Health Science Center at Syracuse gave an instructional tutorial on specific approaches to speech therapy for children with VCFS. The home team was well-represented by pediatric cardiologist Stuart Berger, gastroenterologist Ellen Blank, and an interdisciplinary team from Children's Hospital of Wisconsin discussing social communication, self-esteem, and coping skills, led by social worker, Jim Ellis. The feeding team at Children's also presented, led by Bob Beecher. Susan Oliff-Carneol presented a comprehensive look at Fast ForWord.

Lay members were well-represented on the program, including Julie Squair (Milton Keynes, England), Deborah Gray (Kentfield, CA), and Susan Busch (Brecksville, Ohio). Pam Holland (Richmond, VA) presented a video tape, *A Day in the Life of VCFS* produced with John Ackourney. This tape, made available to Foundation members, is a professional quality documentary of Pam's day-to-day experiences with VCFS.

At the business meeting, a new slate of officers was elected (see the announcement elsewhere in this Newsletter). Future meetings were discussed, including Baltimore (July 21-23, 2000), Florida (2001), and Northampton, England (2002). A suggestion was made to hold the meeting in Washington State in 2003. Donna Landsman handed the presidency over to Julie Cooper who will lead us into the 6<sup>th</sup> Annual Meeting in Baltimore. Outgoing member of our Board, Jeff Landsman, worked behind the scenes to incorporate the Foundation, and the necessary documents were signed by our Member Council. We are now officially *The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.* Thanks, Jeff.

The logistics and mechanics of the meeting were flawless, with every detail personally attended to by our hosts and the local arrangements Chairperson, Susan Marks. With the able assistance of Sharon Phelps, there was a constant stream of activity, both professional and social. The Friday night dinner allowed the kind of mingling between lay and professional members that is unique to our Foundation. Saturday night saw a busload of us going to the Festa Italiana along the lakefront. The camaraderie was palpable and a good time was clearly had by all.

Susan Marks deserves a special commendation for her efforts. She was tireless in making sure everything was perfect, and it was. ❖

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during the meeting.

## Year 2000 Meeting in Baltimore, Maryland!!!

The 6<sup>th</sup> Annual Meeting of *The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.* will be held in Baltimore, Maryland, July 21 - 23, 2000. Program suggestions and a call for papers appears in this edition of the Newsletter.

The meeting will be held at the Best Western Hotel and Conference Center in Baltimore, a short distance from the fabulous Inner Harbor in Baltimore. Very favorable rates of \$95 per night per room (*up to four people per room*) make this a wonderful opportunity to take in one of the nation's hottest tourist locations while attending the meeting. As usual, the meeting will begin Friday, July 21 at noon and conclude Sunday, July 23 at noon. An optional opening reception and dinner will be held in the hotel Friday night...always a great time with a few special surprises this year. Social functions for Saturday are also being planned.

An innovative program will be presented (*see page 5 for an exciting addition to this year's meeting.*), but your participation is key. If you have any program suggestions, please forward them to the Foundation office by email, fax, or snail mail (addresses listed below). An abstract form is included in this Newsletter should you wish to submit a professional/scientific paper, lay presentation, seminar, etc.

The meeting in Baltimore is being hosted by *The Velo-Cardio-Facial Syndrome Mid-Atlantic Support Group*, one of the largest and most active VCFS family support groups in the United States. We have continued to keep our registration fees as low as humanly possible to encourage participation from everyone. Scholarship requests, as in past years, may be submitted in writing to the Foundation office.

Over the past five years, over 1,000 people have taken advantage of this meeting. This means that information has been spread successfully to people who previously may not have had access to it. Come and help us increase that number to new unprecedented heights. The success and life-blood of the Foundation is its membership, the personal contact it promotes, and the open exchange between lay member and professionals. If you have never attended a meeting, let the 2000 meeting be your first. If you have already attended, come back to renew friendships made in past years. In addition to friendship and learning, this year we can give you crab cakes, the National Aquarium, The Maryland Science Center, Camden Yard, boats and more boats, great food, and tons of shopping by the water.

For additional information, contact the Foundation office at the following numbers: phone: 315-464-6590, fax: 315-464-5321, or email: [vcfsef@hscsy.edu](mailto:vcfsef@hscsy.edu). Alternatively, you may contact us through our web site at: <http://www.vcfsef.org>. ♦

## A MESSAGE FROM THE PRESIDENT

Julie Cooper, President of The Velo-Cardio-Facial Syndrome Educational Foundation also represents The Velo-Cardio-Facial Syndrome Mid-Atlantic Support Group. This large support group in the Baltimore-Washington, D.C.-Maryland-Virginia area has been busy making our arrangements for the 2000 meeting. The following is a letter from Julie. . .

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**We have exciting news . . .** we have finally firmed up plans for the **6<sup>th</sup> Annual Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation.** You talked and we listened. Due to the request of many parents from the last meeting, we have scheduled the next conference to be held at the Best Western Hotel near the Inner Harbor in Baltimore, Maryland, **July 21st-23rd, 2000.** We are busy working on many exciting plans for everyone to have fun and learn a lot about new VCFS advances as well as take home practical advice.

### 10 Reasons Why You Want to Come to the Educational Foundation Conference in Baltimore July 21st-23rd, 2000.

10. The Inner Harbor is cool.
9. The rooms are only \$95 a night at the Best Western *for up to 4 people per room.*
8. Four people can share a hotel room for less than \$25 a person, which is even cheaper than the dorm rooms in past years.
7. The hotel is conveniently located next door to the Greyhound Bus Station.
6. The Best Western Hotel has an indoor swimming pool and exercise facility.
5. The Hotel offers free parking, a guest laundry facility, and a food court.
4. Child care arrangements are in the works.
3. The socials and activities are going to be a blast!! Tourism packets are currently being worked on for sites of the Inner Harbor, Maryland, and surrounding cities such as Virginia, Washington, and New York.
2. The speakers are going to be great -- including breakout sessions, medical issues and educational issues.
1. Julie Cooper will never forgive you if we don't attend (smile).

The Best Western is just 3 ½ miles from the exciting Inner Harbor with free shuttle transportation on-the-hour to the harbor. The Inner Harbor is home to the National Aquarium in Baltimore (which features over 10,000 creatures), The Maryland Science Center (with a five story IMAX theater screen and national visitor center for the Hubble space telescope), Port Discovery (a new kid-powered museum featuring three fun-filled floors with hands on exhibits and activities), Pride of Baltimore 11 (docked at the Inner Harbor, it is the only existing replica

of an 1812 topsail schooner), the Top of the World (located in the World Trade Center--one of the world's tallest pentagonal building, offers spectacular views of the city), and many more exciting attractions.

Some other exciting things about the Inner Harbor are the great shops (over 175 shops just in the Inner Harbor), boat rides, free concerts, and great restaurants like the Hard Rock Cafe, California Pizza Kitchen, Planet Hollywood, Phillips Seafood, ESPN Zone and the Cheesecake Factory. There is something to do for everyone at the Inner Harbor and no one is ever disappointed. If you have any questions or suggestions you may call the Educational Foundation Office, or:

Julie Cooper  
11901 Minor Jones Drive  
Owings Mills, Maryland 21117  
(410) 356-2003

or  
The Best Western Hotel & Conference Center  
5625 O'Donnell Street  
Baltimore, MD 21224  
(410)633-9500 or 800-633-9511

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### **VCFS Web site has reached over 10,000!**

In less than two years, the web site of *The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.* has reached over 10,000 people. Created by Kelvin Ringold who single-handedly runs the Foundation Office, the links have been established with many other useful sites, such as The American Cleft Palate-Craniofacial Association and parent support groups.

The web site recently changed its URL to [www.vcfsef.org](http://www.vcfsef.org). Plans are under way to publish the data from the Foundation's data base on the web site shortly, thus allowing all members to know as much as possible about the clinical manifestations of this common syndrome. ❖

### **NEW MEMBER COUNCIL AND OFFICERS ELECTED**

At the business meeting of the Foundation held Friday, July 16, a number of changes occurred, including the signing of the incorporation documents for the Foundation. As part of that document, the Board of Directors was changed to the Member Council. According to the Foundation's by-laws, two new members of the Council were elected to replace Jeff Landsman and Raju Kucherlapati whose terms expired this year. Rhonda McElroy of Washington State was elected to the vacant Lay Member Council seat for a term of three years, and Bernice Morrow was elected to replace Dr. Kucherlapati, also for a term of three years as Professional Member to the Council. Julie Cooper was elected to the presidency replacing Donna Landsman. Robert Shprintzen was reelected to the position of Executive Director for a term of four years. We congratulate the new officers and Council members. More importantly, we thank those members who are cycling off of the Board of Directors. Donna Landsman who served as President has been one of the most active members of the Foundation, fielding dozens of telephone calls to address educational issues thanks to her teaching background that she has shared tirelessly with the membership. Her husband Jeff, an attorney in Madison, WI, gave of his own time and resources to incorporate the Foundation. We might wonder what the Landsmans will do now that they have gained a little time in their busy lives, but we know that they will continue to remain active supporters of the Foundation's mission. Raju Kucherlapati, eminent molecular geneticist and Chairman of the Dept. Of Molecular Genetics at the Albert Einstein College of Medicine was a strong influence in helping to guide the Foundation through its formative years. His presence at Council meetings will be missed. The slate of Council Members and officers are listed below.

#### **Robert J. Shprintzen, Ph.D., Executive Director**

S.U.N.Y. Health Science Center  
750 East Adams Street  
Jacobsen Hall, 7th floor  
Syracuse, NY 13210  
email: shprintr@mailbox.hscsyr.edu

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

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Owings Mills, Maryland 21117  
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#### **Lisa Jennings, Secretary-Treasurer**

(term expires 2001)  
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**Donna Landsman, Past -President**  
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**Deborah Hung Copenheaver, M.S., Editor**  
 (term expires 2000)  
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**Linda Walters, Liaison Chair**  
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**Bernice Morrow, Ph.D., Member Council, Prof**  
 (term expires 2002)  
 Department of Molecular Genetics  
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**Susan Marks, M.S., Member Council, Prof**  
 ( term expires 2000)  
 Children's Hospital of Wisconsin  
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 Milwaukee, WI 53207  
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**Pamela Hunter, Member Council, Lay**  
 (term expires 2000)  
 10265 E. Estates Drive  
 Cupertino, CA 95014  
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**Ronda McElroy, Member Council**  
 (term expires 2002)  
 Family Support Network of WA  
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 email: rhm10@juno.com

**Barbara Dandron, Member Council, Lay**  
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**Ahmad Al-Khattat, Member Council, Professional**  
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 Boughton Green Road  
 Northampton NN2 7AL England

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## Frequently Asked Questions (FAQ)

Past President Maureen Anderson has provided a list of frequently asked questions (FAQs) she has received over the years in her role as President of the Foundation in 1998 and as one of the founders of the *Northeast VCFS Support Group*. We will respond to these FAQs in the Newsletters to follow and will post them on the website, as well. Here are the first two; the remainder will be posted as we develop them.

### 1. *How many of the manifestations of VCFS can I expect my child to have?*

Velo-cardio-facial syndrome, or VCFS, has had over 180 clinical features described, and these are listed on the Specialist Fact Sheet distributed by the Educational Foundation. Probably no individual with VCFS has all 180 findings, but it is also true that no one with the syndrome has only one or two of the findings. Many of the anomalies associated with the syndrome are not apparent at birth, or even in early childhood, primarily because they are behavioral, or in some cases because they are "silent" anomalies, meaning that they are not symptomatic.

For example, nearly all individuals with VCFS have some degree of learning difficulty that does not become apparent in many cases until six, seven, or eight years of age. Structural kidney anomalies are also common, but in most cases cause no clinical problem and are sometimes discovered by chance during an X-ray procedure for some other problem. Therefore, it is important for you to know the full range of possible abnormalities associated with the syndrome so these can be shared with your doctors.

With the type of information provided on the Specialist Fact Sheet, there should be few unpleasant surprises, and abnormalities can be anticipated rather than discovered by chance. Most individuals with VCFS do have multiple abnormalities that become expressed over time, but few, if any, of the late-onset problems pose major threats to health, especially when managed properly.

### 2. *My child is small for his/her age. Will that change?*

There are a number of reasons why children with VCFS may be smaller than normal. In those cases where there is severe heart abnormality, small size is very common, but significant catch-up growth should be expected after definitive repair. It has also been found that many children with VCFS are slightly shorter than one might expect in relation to their parent's height; but, in these cases, height is not abnormally short, just slightly shorter than one might anticipate. However, it should also be pointed out that adults with VCFS are not typically very short. There have not been any studies that have plotted the

height of a large number of adults with VCFS and compared them to the general population, but the clinical experience is that adults with VCFS tend to be of normal height.

There have been a small number of children with VCFS who have been of very short stature and who have required growth hormone treatment. However, this number is so small that it may not be any larger than the number of children in the general population who require such treatment.

Another observation is that the pattern of growth in VCFS may be slightly different than for other children. As infants and toddlers, children with VCFS sometimes lag behind their peers in growth; but, as they approach school age, they do tend to catch up to other four and five-year-olds fairly quickly.

One also needs to be careful over the interpretation of the term "small." Infants and toddlers are often weighed in doctors' offices, but sometimes their length is not measured. Therefore, low weight doesn't always mean that a child is failing to thrive. Because, as stated above, children with VCFS are often shorter than normal as infants, their weight may also be low. This is especially true of children with severe heart anomalies that cannot be completely repaired in the neonatal period. Poor circulation can dramatically reduce linear growth, and it is therefore often true that children who are short do not eat as much as other children, because they do not require so many calories to maintain their growth velocity, and eating more will not make them taller.

It is therefore important to calculate weight in relation to height as an index of proportionality. This is especially important because feeding babies more than they need for their current growth velocity may make their vomiting worse. ❖

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## Exciting Addition to the Baltimore Meeting!

We're adding a new and innovative feature to the 6th Annual Meeting in Baltimore for many parents and professionals. One of the major problems in velo-cardio-facial syndrome is the severe impairments of speech, especially with respect to articulation development, hypernasality, and intelligibility. This year's meeting will therefore feature the first Speech Clinic.

This half day session will be devoted to assessing the specific problems in children with VCFS and showing parents and clinicians how to resolve those problems. A number of expert clinicians will see children with VCFS in a 20 minute session and teach both parents and speech pathologists how to overcome and eliminate the abnormal compensatory patterns that children with VCFS develop. This session is for demonstration and instructional purposes so that these procedures can be implemented by speech pathologists anywhere. Karen Golding-Kushner,

Ph.D., Natalie Havkin, M.S., and Robert J. Shprintzen, Ph.D. have agreed to participate and see your children. Many of you are familiar with these names:

**Dr. Golding-Kushner** is a speech pathologist with over 20 years of experience working with children with VCFS. Her 1985 publication in the *Journal of Craniofacial Genetics and Developmental Biology* was the first research to document the speech, language, and behavioral disorders in VCFS. She wrote a chapter in the textbook *Cleft Palate Speech Management: A Multidisciplinary Approach* that has become the primary resource for clinicians treating the speech disorders in children with cleft palate or hypernasal speech. Dr. Golding-Kushner's doctoral research involved an analysis of velo-cardio-facial syndrome.

**Natalie Havkin, MS, CCC-SLP** is currently the speech pathologist who performs all evaluations and treatments at The Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome at the State University of New York Health Science Center at Syracuse. She has been an invaluable resource to many patients and clinicians from all over the world by helping to guide them through the therapeutic procedures she employs at the Center. She presented a session on speech therapy at the 5<sup>th</sup> Annual Meeting in Milwaukee and will be presenting her latest research at several other national and international meetings over this next year. The combined experience of the clinicians involved in this clinic covers literally thousands of patients with VCFS and represents the largest experience in the world.

*Bring along any and all interested speech pathologists* so they can sit in on the demonstrations and learn the techniques for resolving the severe speech impairments seen in VCFS. If you are interested in participating in this session and would like to have your child seen, write, email, or fax the Foundation Office immediately for details.

While we intend on seeing as many children as possible in this time period, sessions will obviously be limited. To participate, call Kelvin at 315-464-6590, or email the Foundation Office at [vcfsef@hscsyr.edu](mailto:vcfsef@hscsyr.edu), through the web site at [www.vcfsef.org](http://www.vcfsef.org), or by fax at 315-464-5321. Please include your child's date of birth when you call. This clinic will be most beneficial for children who are 2 years old and above.

See you in Baltimore! ❖

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**Form For All Submissions**  
**Sixth Annual Meeting, July 21-23, 2000**  
**The Velo-Cardio-Facial Syndrome Educational Foundation**

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**TITLE:**

**SUBMITTED BY (underline person presenting):**

**TYPE OF PRESENTATION (check appropriate category):**

Professional paper                      Professional Seminar                      Clinical case presentation

Lay Presentation: Sharing the Good Times                      Lay Presentation: Helpful Hints

Other (describe) \_\_\_\_\_

**ADDRESS:**

**TELEPHONE:**

**FAX:**

**E-mail:**

**TIME REQUESTED FOR PRESENTATION:**

**AUDIOVISUAL EQUIPMENT REQUIRED:**

Type or print the abstract (without title or authors) in the space provided below. Submit 3 copies to be postmarked by April 14, 1999. Mail to Dr. Robert J. Shprintzen at: *Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome, Jacobsen Hall 707, State University of New York Health Science Center, 750 East Adams St, Syracuse, NY 13210 USA*. Abstracts may also be faxed (1 copy) to 315-464-5321 or emailed to shprintr@mailbox.hcsyr.edu by April 14<sup>th</sup>.

