

VCFSEF News

VCFSEF, Inc. Newsletter

Fall, December 2000

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The web site will soon feature summaries of the talks presented by faculty from the Baltimore meeting, including those of Dr. Bernice Morrow and Dr. Stephan Eliez. The Foundation appreciates the generosity and openness of these professional members. More presentations will appear shortly.

*2001 Annual Meeting,
Deerfield Beach, FL
Details on page 2.*

The Baltimore Meeting a Huge Success

The 6th Annual Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation, Inc. was held in Baltimore at the Best Western Hotel and Conference Center in Baltimore this past July 22-24. The meeting was the most successful in the brief history of the Foundation; a difficult task considering the quality of past meetings in New York, Stanford, Boston, and Milwaukee. There were over 300 registrants, including over 50 children who attended the speech clinic, leg pain clinic, etiquette classes, and self-esteem workshop. There are so many people to thank that we can only hope we forget no one.

The Mid-Atlantic Support Group hosted the meeting. Julie Cooper was involved in essentially every aspect of planning and execution, and every member of her extended family was visible throughout the course of the meeting to help with child-sitting, setting up, social functions, etc. Brian Cooper proved an exceptional group leader, managing to organize and direct a Saturday night event at the Inner Harbor including dinner at Planet Hollywood. Valerie Kutchman organized an incredible array of activities for the children, sacrificing her own attendance at the lectures to supervise the many children being watched by the volunteers. Amy Ousterhout provided personal resources and a grant to support the meeting for which the Foundation will be forever grateful. We must also mention Annette Cooper (and, of course, Alex Cooper) and Gertie Brownstein who gave of their time to help with the kids. Laura Dvornicky and Diane Holland organized fund raisers, and the proceeds went to support the meeting.

The staff at the hotel were very accommodating, and our success at having our first self-contained meeting at a hotel proved very popular. The faculty who presented were uniformly superb and the program flowed smoothly throughout. Audio tapes from the meeting are available through Conference Copy, Inc. (they may be accessed through the Educational Foundation's web site). The Friday night dinner was the largest we ever had with over 120 in attendance, and the convivial atmosphere was genuine and lasted all evening. Some pictures from the meeting are displayed on these pages.



A packed Meeting Room at the Baltimore Conference

Announcing the 7th Annual Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc

Following on the success of the 6th Annual Meeting in Baltimore last summer, The Foundation has decided to hold the 7th Annual Meeting in a self-contained environment at the Hilton Hotel in the fashionable Boca Raton and Deerfield Beach area of Florida. The Hilton is a wonderful facility close to the ocean and beach, golf (there are 6 championship courses nearby), and shopping (at the famous Mizner Park in Boca Raton). The hotel is close to both the Fort Lauderdale and Palm Beach International Airports. We have negotiated a daily rate of \$75 per room (not per person). Details of the program will be made available shortly, but we can tell you that we will repeat the very popular speech and leg pain clinics that were held last year. Also returning will be Dr. John Walkup of Johns Hopkins to discuss the issue of self-esteem in children with VCFS. Guest speakers this year will include Antonio Baldini and Elizabeth Lindsay of Baylor Medical College in Houston, two of the major researchers in unraveling the mysteries of the genetics of VCFS. We will be adding many new features to this year's meeting and the announcements of the initial program will follow shortly in the next Newsletter.

Come to the beautiful beach resort of Deerfield Beach/Boca Raton and learn the latest developments in clinical care and research while sharing sun and fun with friends from all over the world who share your common interest in VCFS.

We are trying to give the newsletter a more professional appearance. I hope you find it easier to read. Let me know via email to The Foundation (Kelvin)

Call for Dues

Dues for the calendar year 2001 should be received by January 31. Please send checks or money orders to the Foundation Treasurer, Lisa Jennings at 385 North Street, Weymouth, MA 02191. Please make checks out to The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. Dues are \$25 for a single membership, \$30 for a family membership, and \$10 for a student membership. We would like to remind the membership of the following.

1. Dues have not increased since the inception of The Foundation.
2. Dues are voluntary, but the Foundation could not function without them.
3. If paying dues is impossible for you



At the Friday night dinner, from left to right: Doron Gothelf (Tel Aviv, Israel), Wendy Kates (Baltimore), Stephan Eliez (Stanford, CA), Demetri Papolos (Westport, CT); Stu, Tzipora, Karen, and Leor Kushner (East Brunswick, NJ)

right now, please let us know with a letter so we know to keep your membership intact.

4. We also have two separate funds to which you may make a separate donation. The Caitlin Lynch Memorial Fund was initiated by the Lynch family in loving memory of their daughter. This fund has been used to provide free tuition and some expenses for people to come to the annual meeting who might not otherwise have been able to attend. Since the fund's inception, The Foundation has provided assistance for over 50 people. Any donation would be appreciated, but we suggest a gift of \$10.

5. The Tony Lipson Memorial Fund was established in memory of the beloved pediatrician and geneticist from Sydney, Australia who championed the treatment and study of children with VCFS in Australia and was the guest speaker at the First Annual

Meeting of The Foundation. Donations to this fund help support attendance at the meeting by a representative from Australia. A gift of \$10 is suggested.

Although dues are voluntary, The Foundation depends on these funds for the production of the Newsletter, maintenance of the web site, and the running of the annual meeting. We will soon be faced with a decision to drop people from the mailing list for the Newsletter if they have not paid dues nor asked for a waiver of dues. The Foundation runs on a very thin margin with its annual budget, and we therefore ask for your support. Thank you.

The Foundation Web Site...

will be going through some renovations after the first of the year.

Besides a graphical face-lift, we intend to make it a bit easier to navigate, and find the information we do have available; and to add some documents we've had translated into Spanish.

We have some other goodies planned, but I won't say -- in case I can't deliver (smile). Have a great day!

Kelvin

The Newsletter Has a New Editor !

Eileen Marrinan has been elected to the post of Editor of the Educational Foundation and will begin her tenure with the next issue, which should follow this edition by only a month or two. Eileen has had a long and strong commitment to the study and treatment of velo-cardio-facial syndrome. She is a speech pathologist who has focused exclusively on pediatric disorders in her 20 year career. After completing her Master of Science degree in speech pathology at the University of Wisconsin in Madison, she went on to complete a Master's of Public Health at Harvard University in Boston. She worked at the Cleft Palate and Craniofacial Clinics at Children's Hospital in Boston for 14 years. She is currently affiliated with the National Birth Defects Center in Waltham, MA just outside of Boston. She continues to specialize in treating children with cleft palate, craniofacial anomalies, and related disorders. She is in the process of bringing her expertise in public health issues to construct a new interdisciplinary team. Eileen has published and presented extensively, has taught graduate courses at several Boston universities. Her commitment to children with VCFS has been demonstrated on numerous occasions, including her participation in annual Educational Foundation meetings.

The Foundation would like to extend its heartfelt thanks to our outgoing Editor, Deborah Hung Copenhaver, a genetic counselor at Children's National Medical Center in Washington, D.C., who managed to find time in her very busy schedule for this newsletter that has reached so many people worldwide.

Audio Tapes from 2000 Conference are available from the vendor. See the link on the Foundation web site at: www.vcfsef.org/vcf_ref.html



Brian Cooper leading some of the meeting participants to Planet Hollywood along the Inner Harbor in Baltimore.



At the Friday night dinner, from left to right: Ahmad Al-Khattat (Northampton, England), Eamon and Maureen Anderson (Salem, NH) and Hazel Squair (Milton Keynes, England.)

A Restatement of Our Mission

Robert J. Shprintzen, Ph.D.
Executive Director

This past year has been an interesting one for the Velo-Cardio-Facial Syndrome Educational Foundation. We have met challenges and come out stronger. We have taken several bold new steps. We have taken on new directions. The operational word in these previous sentences is the shortest one: **we**. Since its inception, The Foundation has become an organization of approximately 2,000 members, the large majority joining long after the formation of The Foundation in 1994. Therefore, it occurred to me that many, if not most, of our members may not understand what The Foundation is all about. Although our Mission Statement is prominently displayed on our web site at www.vcfsef.org, I suspect that many people have not read it. It is likely that many people believe that The Foundation is a family support organization. It is not. Others may believe that The Foundation is a mechanism for raising funds to promote research or patient care. It is not. Still others may believe that The Foundation is an arm of a hospital or a group of doctors being used to promote referrals for medical services. It is most definitely not. Here is the Mission Statement:

Mission Statement: The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

(The Foundation) is an organization comprised of both professional and lay people whose purpose is to educate the public, the scientific community, families of individuals with velo-cardio-facial syndrome, and individuals with velo-cardio-facial syndrome (VCF) about this common genetic disorder. The Foundation will act as an advocate for both patients with VCF and the professional community treating this disorder. The Foundation will provide a forum for discussion of the problems, treatments, or

achievements associated with VCF and its management.

As implied above, **we** are the Foundation. **We** are the organization. The Foundation is **us** and it is our mechanism for informing as many people as possible about velo-cardio-facial syndrome.

In order to further understand the purpose of The Foundation, it is important to examine its birth. In 1994, there were relatively few people who knew about VCFS. This was true of both the professional community and the lay public. At about the same time, the internet was beginning to become a functional tool and people were beginning to use it to learn about the syndrome. However, there was very little available material outside of professional journal publications. The time seemed right to find a mechanism for providing information that would be current, accessible, and understandable using modern technology and personal contact as mechanisms for spreading the word. Therefore, approximately a dozen people, both professional and lay people, banded together to discuss the formation of an organization that would meet an educational need. The Foundation was formed following a face-to-face meeting of these people in my office in the summer of 1994 where a set of by-laws was hashed out. The next step was to bring as many people into the process as possible, and the First Annual Meeting of the Foundation was set for a scant few months later in March of 1995, in part because one of the international advocates for VCFS research, Tony Lipson of Sydney, Australia, was going to be in the United States and we saw an opportunity to have him as a guest speaker. That meeting included the first official business meeting of The Foundation where a slate of officers was elected and our by-laws ratified. Approximately 150 people attended that meeting in New York City. Our first President, Joe Abruzzi from Weston, CT, ushered the Foundation through its first year and a half, then handing the reins over to Harry Keleshian of Greenwich, CT. These two remarkable men, both parents of people with VCFS, served as models of dedication for a succession of equally remarkable women lay members who have

served as Presidents of The Foundation, including Maureen Anderson (Salem, NH), Donna Landsman (Madison, WI), and Julie Cooper (Baltimore, MD). Elected members of our Board of Directors and committee chairs, although initially primarily from the New York metropolitan area, has since expanded to geographically diverse locations, including California, Florida, Wisconsin, Massachusetts, Maryland, Virginia, Washington State, Washington, D.C., Toronto, and England. A concerted, altruistic, and ultimately very fair process was implemented by the Board and its Officers to spread the Foundation's umbrella over as large an area as possible so that no one could confuse its interests with the agendas of one or two individuals. As part of its by-laws, we have placed term limits on every elected official to assure the constant cycling of fresh ideas into every aspect of the governance of the Foundation.

Why is it important that the Foundation stick to its stated mission? Why not, after all, try to raise large sums of money to fund research? Why not be a support group at the national or international level? Why not act as a referral service for affiliated professionals? The following thoughts are my own, but they have been discussed in detail at our Board of Directors meetings, and so far, we all seem to be on the same wavelength, but these issues should be answered one at a time.

Why not raise large sums of money for research or clinical care? Besides the fact that this task is difficult (raising money, that is), the primary reason is that the search for money is a competitive one. One of the truly wonderful aspects of the Foundation is the strong bond that has been forged between all members, professional and lay, and the notion that we are all working towards the same goal (education) together. Unless a sum of money equal to the gross national product of Finland could be raised, how would we determine who is most deserving? In order to foster cooperation and collaboration, the Foundation must remain completely neutral towards its membership. In other words, no single member should have a base of power that would be inconsistent with the

PREREGISTRATION FORM

(Preregistration will be accepted until June 30, 2001)

Seventh Annual Meeting, July 20 - 22, 2001, Deerfield Beach, FL The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

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: The entire meeting will be held at the Hilton Deerfield Beach/Boca Raton Hotel. The hotel is close to both the Fort Lauderdale and Palm Beach airports and is also close to Boca Raton. All rooms are \$75 (rate per room, not per person). Reservations should be made directly with the hotel or with Hilton International. Call 1-800-624-3606 or 1-800-HILTONS, you are attending the Velo-Cardio-Facial Syndrome Educational Foundation meeting. The hotel has a beautiful pool area, exercise facility, and restaurant. The beach is two miles away. Golf is readily available with 6 courses accessible to the hotel. Shopping at the Mizner Park is close to the hotel.

Registration Fees: *Registration includes attendance at the meeting, continental breakfast, and refreshment breaks. The annual dinner is a separate fee. Enclose a check or money order made out to **The Velo-Cardio-Facial Syndrome Educational Foundation.** For registrants from outside of the U. S., please send a bank draft payable in U.S. dollars*

Single preregistration, member	\$50.00 U.S. _____
Family preregistration, 2 members (please list names below)	\$70.00 U.S. _____
Single preregistration, nonmember:	\$60.00 U.S. _____
Family preregistration, 2 nonmembers (please list names below)	\$90.00 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:	\$40.00 U.S. _____
Student nonmember preregistration:	\$50.00 U.S. _____
Optional Friday Night Welcome Dinner:	\$30.00 per person _____

Total Enclosed _____

Please list all family members to be registered (family registrations only):

I would like my child seen at the speech clinic _____ I would like my child seen at the leg pain clinic _____

I am interested in a sibling workshop _____ I am interested in a teen/young adult get-together _____

I am interested in child care during the meeting _____ I am interested in sharing a room _____

Registration fee at the door will be an additional \$10.00 per person, if space is available.

Send checks with completed form made payable to: Velo-Cardio-Facial Syndrome Educational Foundation

address: c/o Dr. Robert J. Shprintzen, Jacobsen Hall 714

Upstate Medical University

750 East Adams St., Syracuse, NY, 13210

Receipts will be available at the door.

Velo-Cardio-Facial Syndrome Educational Foundation Board Meeting & Business Meeting

7/21/00

Baltimore, Maryland

Board members present: R. Shprintzen (chairman), J. Cooper (presiding president), R. McElroy, B. Morrow, S. Marks, B. Dandron, A. Al-Khattat, P. Holland, D. Landsman, J. Landsman.

Budget & Treasury report:

501(c)3 (Non-Profit) status: Jeff Landsman has submitted all required information to the IRS, we are awaiting final favorable tax determination letter. No problems are expected.

In process of setting up a new business checking account. All deposits from this meeting will be made to the new account. Old account at Syracuse Foundation office will be paid down until balance is zero.

Going into Baltimore meeting, balance was around \$2,000, down about \$1,000. Lower balance is partly due to the decrease in dues collection (which is voluntary). Also, registrations were slightly down in Milwaukee meeting in 1999.

\$10,800 in registration fees from this conference.

\$10,300 in conference center expenses.

Local support in Baltimore has paid for many of the expenses.

Not yet included are some additional travel expenses for guest speakers; estimated at \$3,000 - \$4,000.

Another dues notice will be going out shortly to all members.

Future Meetings:

2001 - Miami Children's with Hotel accommodations. Local contact: Barbara Dandron.

2002 - Northampton, UK. University to assign an administrator. Dorm rooms: individuals \$30/night; Hotels - families \$60 / night.

Open issue: Getting US members & others to the UK at reasonable rates. Proposal: set aside some funds for financial support from US to UK travel. Dates confirmed: July 27-28, 2002. Discussion regarding the controversial CHOP-affiliated proposed 2002 conference in UK.

2003 - Washington State. University of Washington dorms. Local contact: Rhonda McElroy.

Discussion regarding fund-raising, funds for lobbying, possible parent coalition.

2004 - Proposed Atlanta, GA meeting site. Presentation by Karlene Coleman. Institutions interested in sponsoring conference: Children's Healthcare of Atlanta, Emory University, Center for Disease Control. The Children's Foundation of Atlanta is interested in supporting the meeting with both a scientific & parent focus. The Child Life center is also involved. Can offer CMEs.

Board presented proposal to membership at Business Meeting for consideration.

Proposed nominations for 2000-2001 VCFSEF Board:

President - Barbara Dandron (FL)

Member (lay) - Nancy Robbins (VA)

Member (lay) - Linda Opper (FL)

Member (professional) - Robert Beecher (WI)

Newsletter Editor - Eileen Marrinan (MA)

Voted & accepted by membership at Business Meeting.

FORM FOR ALL SUBMISSIONS

Seventh Annual Meeting, July 20-22, 2001

The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

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 (standard equipment will be a computer with LCD projector, VHS VCR, and single slide projector):

Type or print the abstract (without title or authors) in the space provided below. Submit 3 copies to be postmarked by May 1, 2001. Mail to Dr. Robert J. Shprintzen at:

Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome, Jacobsen Hall 714, Upstate Medical University, 750 East Adams St, Syracuse, NY 13210 USA

Abstracts may also be faxed (1 copy) to 315-464-5321 or emailed to shprintr@upstate.edu by May 1.



At the Saturday night dinner at Planet Hollywood, from the left: Jeff Landsman (Madison, WI) speaking with Julie Cooper (Baltimore), and Brian Cooper chatting with Cheryl Abruzzi (Weston, CT).

stated mission and the by-laws of the Foundation.

There are already many venues for funding research. In fact, there has been no shortage of money spent on research into the issues involving VCFS. The National Institutes of Health has already devoted millions of dollars to scientists studying VCFS, and other Foundations and granting agencies have also been receptive to applications from our membership. We need not reinvent the wheel by trying to take over that role ourselves.

Another issue is the fact that professional members of the Foundation may wish to raise funds for their own programs or institutions for operating costs. We should not present a conflict of interest to our members by having competing interests in the process of raising money. Being loyal to the Foundation and its financial needs may be in conflict with the demands of places of employment and their financial needs.

Thankfully, the Foundation has never run at a deficit. We have managed to pay all of our bills for the annual meeting and the Newsletter and still have money in the bank. Looking at this another way, using very limited financial resources, we have been successful in reaching thousands of people using only dues, registration fees, and several donations from members that were specifi-

cally targeted to the educational mission of the Foundation.

Why not be a support group at the national or international level? Because there are already a large number of local support groups, and why would we want to usurp their missions and goals? In fact, it is easier for people who are geographically nearby and who know the local community to provide the type of understanding and direction at the personal level that people from out-of-town can not. What the Foundation can do (and does) is to provide educational material to any local support group, to list them on the Foundation's web site, and connect them with local professional members in order to provide them the opportunity to interact. If our mission is to educate, then local support groups represent the true grass root effort.

Why not act as a referral service for affiliated professionals? Although being a referral source would clearly increase the number of professionals who would join the Foundation, do we really want people to have that as their motivation? How do we know if they are qualified? What is the responsibility of the Foundation if we recommend a particular professional whom does not get good or even adequate treatment outcomes? How do we deal with several different professionals from the same field who are in

the same area and are therefore in competition?

The obligation of our membership is to fulfill the mission of the Foundation. Therefore, it is my opinion that we need to eliminate all of the other distractions that get in the way of the openness, the camaraderie, and the collaboration that has thus far marked the activities of the Foundation. I believe this opinion is consistent with the impetus behind the establishment of the Foundation and is in the best interest of the entire membership.

I would invite the membership of the Foundation and the readership of the Newsletter to respond to this article with letters or emails, and if a dialogue is established, then we can do so within the pages of this Newsletter.

VCFSEF Newsletter

The VCFSEF newsletter is the official publication of the Velo-Cardio-Facial Syndrome Educational Foundation, an international not-for-profit, self-help organization dedicated to providing support and information to individuals who are affected by Velo-Cardio-Facial Syndrome, their families, physicians, and other practitioners.

This document is published for informational purposes only, and should not be used as a substitute for competent, medical advice.

Executive Director . . . Robert J. Shprintzen (NY)
 President Barbara Dandron (FL)
 Sec / Treasurer Lisa Jennings (MA)

Professional Council Members:

Ahmad Al-Khattat (England)
 Bernice Morrow (NY)
 Robert Beecher (WI)

Lay Council Members:

Linda Opper (FL)
 Ronda McElroy (WA)
 Nancy Robbins (VA)

Editor Eileen Marrinan (MA)
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