

VCFSEF, INC NEWS

Eileen Murrinan, MS, M.P.H. Editor
 Kelvin P. Ringold Design & Layout

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Say Good bye. . . Say Hello

Outgoing Executive Director: Robert J. Shprintzen

You may have heard some nasty rumors that circulated after our 9th Annual Meeting of The Foundation in San Diego. One rumor was that I retired, the other was that I left Syracuse and moved to New Jersey. Neither is true!

What IS true, is that The Foundation has moved to New Jersey with a new Executive Director. The rumors probably resulted from confusion about what The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. actually is, what my involvement has been, and what my real job is. The best way to clarify all of this is to give a brief history of The Foundation and explain why I chose to decline reelection as Executive Director.

First, let me congratulate the new Executive Director of The Foundation, Dr. Karen J. Golding-Kushner who was elected to office at the business meeting of the Foundation on August 1st. Dr. Kushner is a speech-language pathologist who has been involved in the study and treatment of VCFS almost from the beginning of the syndrome's delineation in the 1970s. In fact, her doctoral thesis involved a study of the anatomy and physiology of the speech mechanism in children with



Dr. Shprintzen, cheerfully passing the reigns... to Dr. Kushner.

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From the new Executive Director: Karen Golding-Kushner

I am honored and excited to have been elected your new Executive Director. I have been involved with the Foundation from its inception, and have watched it grow from a fledgling group of a few professionals and parents in the New York area to an organization that reaches around the world. I would like to take this opportunity to tell you a little about my background and how I came to be involved with this wonderful group.

I am a speech-language pathologist with a B.S. in Speech Pathology and Audiology from the University of Albany (NY). The first child assigned to me as a clinic student in Albany (way back – 30 years ago- in 1973 or 74) was a four-year-old girl with repaired bilateral cleft lip and palate. I no longer remember her name, but can picture her clearly, with her blue eyes, blond curls, and sweet manner. This little girl, who by now must be in her mid-30s, cannot possibly imagine that it was through my experience with her that I became interested in craniofacial disorders. After graduating from Albany, I went to the University of Pittsburgh to work toward my Master of Arts degree in Speech-Language Pathology. I chose Pitt because Dr. Betty Jane McWilliams, one of the foremost experts in cleft palate, was on faculty there. I studied with her and other excellent pro-

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Dr. Eliez of Geneva, Switzerland addresses a full house.


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Good Bye *continued.* . .

VCFS and in children with several other genetic disorders. She served on The Foundation's first Board of Directors, and has presented tutorials at many of our annual meetings. Many of you will recognize her name because she is author of the book that has become the backbone of treating speech disorders associated with cleft palate and velopharyngeal insufficiency, *Therapy Techniques for Cleft Palate Speech and Related Disorders*. More important than her credentials as a scientist and clinician, however, is her commitment to The Foundation and its members. She is an energetic take-charge person who will serve The Foundation tirelessly. She has, in fact, already started and has brought a degree of vigor to the office that is welcomed.

So, what of the former Executive Director and these nasty rumors that he is fading out of sight or moving to the warmer climes of New Jersey (no, New Jersey isn't tropical, but it is warmer than Syracuse). I am not retiring, I am not moving. I am also not abandoning The Foundation. It is simply time for people with new ideas and new energy to put their stamp on The Foundation. I think that there may be confusion about the nature of The Foundation leading to the assumption that my role as Executive Director of The Foundation was my job and that that The Foundation is affiliated with Upstate Medical University in Syracuse. Neither is true. As for the first assumption, the position of Executive Director of The Foundation is voluntary, and I served the Foundation at the same time as I worked as Director of the Communication Disorder Unit and its divisions, including the Center for the Diagnosis, Treatment, and Study of VCFS at Upstate Medical University. The Foundation pays no salaries, and 100% of the money it takes in through dues and registration fees for the annual meeting go towards

fulfilling its mission of educating professionals and the public. The income received by The Foundation goes to maintaining its web site, producing the Newsletters, mailing out materials, and holding its annual meeting (the single largest expense by far). We have never compensated anyone for any of the time they have spent in working for the Foundation...not a single penny. The Foundation has never had much of a

"It is simply time for people with new ideas and new energy to put their stamp on The Foundation. . .

balance in its checking account by design.

The second assumption, that The Foundation is somehow affiliated with the hospital and medical school that employs me, would be a violation of our by-laws. A clause in The Foundation by-laws mandates that The Foundation cannot be an instrument for advancing the agenda of any member nor any institution. In fact, I wrote this clause of the by-laws because in my professional career, I saw a number of instances in which institutions that were seeking patients, funding, or donations set up "organizations" that functioned in reality as an arm of the institution or an advertisement and recruiting mechanism for it. I find this type of "front" to be ethically questionable. I have also seen professional societies that became so closely aligned with a single institution that they alienated potential members, became cliquish, and prevented people from participating fully in the organization. The mission of The Foundation is clear and unambiguous. Our purpose is to educate. As such, we must be inclusive of everyone, close

our doors to no one, and have a purpose so altruistic that it cannot be questioned. I believe we have done that. The following brief review of our history will illustrate how we have succeeded.

The Velo-Cardio-Facial Syndrome Educational Foundation was formed in 1994 when a group of about 15 professionals and lay people met in my office when I was working in the Bronx at Montefiore Medical Center. We recognized that not enough professional and lay people knew much about VCFS. We agreed that one answer was to create an organization to spread information about VCFS but knew that that this organization had to be independent of potential influence from individual institutions. The reason for this decision was simple. Professionals might be

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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.

Caitlyn Lynch Memorial Fund

Debra Gollehon
Linda Oppen

Tony Lipson Memorial Fund

Debra Gollehon
Linda Oppen

In Honor of Robert J. Shprintzen

Bob Beecher
Fred Berg
Stephan Eliez
Deborah Gray & Sidney Sall
Pam Hunter
Lisa Jennings
Karen Golding-Kushner
Kelvin Ringold
Nancy Robbins
Julie Squair

General Donations

Richard Ehrreich
Frederika Millet-Camozzi

Ninth Annual Meeting Summary

Annual Meeting A Huge Success: Over 260 Meet in San Diego

The 9th Annual meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. was held in San Diego, California from August 1 – 3. Registration for the meeting exceeded 260 and included attendees from the U.S., Australia, Canada, Israel, Mexico, Norway, Switzerland, and the United Kingdom. There was a good mix of professional and lay members, with professionals comprising over 35% of the audience representing the fields of genetics, psychiatry, child neurology, developmental pediatrics, neuropsychology, speech-language pathology, audiology, otolaryngology, psychopharmacology, social work, education, and others. Many students also attended. The program was exceptionally strong and included presentations on diagnosis, treatment, education, social issues, and advocacy. Cutting edge research was presented on psychiatric issues, brain imaging, new medical treatments for psychiatric disorders, and the analysis of muscle tissue in the pharynx. There was, as always, strong participation from the audience with ample time for questions and discussion. As in years past, speech, feeding, and leg pain clinics were held throughout the meeting, and over 50 children were seen by the professionals who volunteered their services to conduct the clinics.

A new slate of officers was elected at the annual business meeting, and includes:

Executive Director: Karen J. Golding-Kushner, Ph.D., East Brunswick, NJ, USA

President: Monica Townsend-Mervin, Powder Springs, GA, USA

Board of Directors, Professional Member: John (Jay) Riski, Ph.D., Atlanta, GA, USA

Board of Directors, Lay Member: Heather Mellor, Manchester, UK
(corrected 1/13/04)

These newly elected officers will join the balance of the Executive Council whose terms continue:

Secretary-Treasurer: Lisa Jennings, Weymouth, MA, USA

Board of Directors, Professional Members: Stephan Eliez, M.D., Geneva, Switzerland and Wendy Kates, Ph.D., Syracuse, NY

Board of Directors, Lay Members: Fred Berg, Sterling Heights, MI, USA and Linda Opper, Boca Raton, FL, USA



Dr. Robert Beecher consults with parent during speech clinic.

Maureen Anderson will continue as Liaison Chair and the new Executive Director and Board will be making other committee appointments shortly.

Completing their terms on the Board were Bob Beecher (Board of Directors, 2000-2003), Pam Hunter (President, 2002-2003), Nancy Robbins (Board of Directors, 2000-2003), and Robert J. Shprintzen (Executive Director, 1994-2003). The Foundation thanks those leaving office for their dedicated service.

The Foundation also cemented its international involvement with the election of Regional Directors who will act as liaisons with professionals and support groups around the globe. The new Regional Directors of The Foundation, who will report directly to the Executive Director, are:

- Pacific Rim (Australia and Asia): Stephen Russell, LL.B., Brisbane, Queensland, Australia
- Central and South America: Antonio Ysunza, M.D., Mexico City
- Europe, Continent: Stephan Eliez, M.D., Geneva, Switzerland
- Europe, British Isles and Ireland: Ahmad Al-Khattat, M.B.B.Ch., B.Sc. and Julie Squair
- Middle East: Doron Gothelf, M.D., Tel Aviv, Israel

We look forward to continuing our work to disseminate educational information about VCFS throughout the world.

We're Not alone

By Maureen Anderson

It's March 1989 – Boston, Massachusetts USA. . . Okay, so now we're parents! Yay! But wait...not only do we *not* have a Parenting 101 handbook, it seems our child is missing a slice of ole' #22. Unexpected to say the least!

I remember when my husband and I first received THE DIAGNOSIS. We had tried for many years to have biological children undergoing just about every indignity that doctors can throw at infertility patients. When we finally were fortunate enough to adopt a wonderful little boy, he brought with him some cardiac 'issues'. But, hey, we could deal with that. We didn't hear the V word until Eamon was about three years old. VCFS came at us from out of the blue!

As time went on, and our brave little boy's challenges were more evident, it also became evident that it was psychologically difficult for us to face these challenges alone. But it was clear that none of our parent peers could relate to our situation. They would nod, look uncomfortable, and sometimes say things like "You'd never know - he doesn't look...(fill in the blank)" or "Velo-what?" And our families were in denial. I suppose they were trying to make us feel better. "He'll be fine - just give him time." "You worry too much!" (They still say these things to this day!)

We could deal with the more tangible issues, we thought. The physical challenges were mostly fixable. But our fears for the future were sometimes overwhelming - "Will he ever be able to live on his own?" "Are the real-world sharks going to eat him alive?" "Will WE ever be able to live on OUR own?" And the big one (insert organ music here) "What about the

psych issues?" Words like 'normal', 'typical', or 'average' became like splinters that we couldn't dislodge from our psyches. Eventually, words like 'special ed' and 'learning disability' entered our everyday lexicon.

After allowing the diagnosis to percolate a bit, my husband and I decided that, since there were supposedly so many more of us out there in the same boat, swimming in

"Before starting a support group you must evaluate your personal situation to determine whether you are ready and able to do so. "

the same gene pool, we wanted to find them. But the only name and phone number on any 'VCFS contact list' was that of a woman whose child was an adult and had just about every one of the 150+ manifestations of VCFS. When we spoke, she proceeded to tell me every one of those challenges in detail culminating with a daunting psychological profile. Now, the woman was sincerely well-intentioned and most likely felt that she was being supportive and informative. Of course, after I hung up from that phone call, I put my head down on the kitchen table and cried.

But, after I dried my eyes and wiped off the table, in a scene that closely resembled a scene from *Gone With the Wind*, I (in my most Scarlett O'Hara-type voice) vowed (with my fist in the air), "As God is my witness, I will never let anyone go through that again!"

When my husband arrived home that

day, I told him about my phone call and we talked about starting a local support group for VCFS families. A/K/A "How to secretly help yourselves under the guise of helping others." Now, we had no idea what this entailed but were sufficiently naive enough to give it a try.

Not having a clue about support groups, I called upon someone who was integral in helping us get a diagnosis for our son - Eileen Murrinan, who was a SLP at Children's Hospital in Boston at that time. She worked closely with us in our new endeavor, calling patients (she couldn't give us the information due to confidentiality constraints) and helping us gather a team of knowledgeable, caring Children's Hospital professionals to talk at our first meeting.

Six weeks later, the Northeast VCFS Support Group had its first meeting at Children's. We met in a room in the Harvard Medical School Library and it was a standing room only gathering with 50 attendees! Now, this may sound like a small group but, when you think about the fact that this was about nine years ago when VCFS was recognized even less, this was an amazing feat.

I still remember the expressions on many faces as they heard stories from other VCFS parents at that meeting. They were so encouraged to meet people (both parents and medical professionals) who could understand their unique challenges and joys. Although meeting parents and hearing stories was frightening to some, the overall tenor of the meeting was positive. We now have almost 200 families and medical professionals on our mailing list.

The Northeast VCFS Support Group

We're Not alone *continued...*

has experienced ebbs and flows over the years. And the advent of the internet has made the quest for information easier and makes the need for personal contact unnecessary for some families. But our group still tries to meet twice a year - sometimes socially so the children can interact. We also have a database by which we connect those looking to talk with others who have similar situations.

Starting our group has been a most rewarding endeavor. I have made lifelong friends and have learned so much about what the future might hold for our little guy. I have been privileged to share in the joys and, yes, the challenges of VCFS families. And, most importantly, I am constantly amazed at the strength of these families and the spirit of the children who are coping with VCFS. They are all inspirational!

If you are interested in stating a VCFS Support Group in your area and would like more information, please contact Maureen Anderson at MLADJA@aol.com or (603) 898-6332.

Following is a synopsis of a paper compiled by Maureen Anderson. If you are interested in receiving the entire article, please contact Maureen at (603) 898-6332 or MLADJA@aol.com

WHAT IS A SUPPORT GROUP?

A support group is two or more people who share the same health care problem or life situation. Support groups should provide a safe, non-judgmental and confidential outlet and offer resources. Support groups should NOT attempt to 'cure' people, diagnose or recommend medications

STARTING A SUPPORT GROUP

Before starting a support group you must evaluate your personal situation to

determine whether you are ready and able to do so. Do you have the time and energy? Is your family ready? Are you prepared to put personal beliefs on hold? Can you share authority?

DEVELOPING A MISSION STATEMENT

One of the best ways to determine the basis of the group is to develop a Mission Statement. This includes goal-setting and how to accomplish those goals. Issues to consider as goals are emotional support, educational support, social action, or a combination.

LEADERSHIP AND SHARED RESPONSIBILITY

Your group needs a leadership structure such as peer or professional leadership, or your group can be a discussion group. You can also consider having elected officers, shared leadership or a flat structure.

GROUP FORMAT

Your group can have telephone contact, meetings, or both.

MEETINGS

Where? Logistically, this can be difficult for VCFS groups as they usually cover a broad area. A centrally located facility is probably the most practical. Private residences can be tricky, as these tend to lend an air of extreme informality which makes it difficult for a group to stay focused.

When and how often? Will you meet at a certain time of year?

Weekly? Monthly? How long? There should be a definite beginning and end of the meeting. The length of the meeting depends upon the agenda.

MEETING STRUCTURE

Set agenda - Meetings can become bogged down if there is not an agenda

with specified time limits on each segment.

Choose facilitator - This person should be familiar with facilitating discussions and following an agenda.

Set ground rules - These should be simple and based upon respect. The rules should be in writing and given to each attendee.

Determine decision making process - Roberts Rules of Order are a good source

PROMOTING YOUR GROUP

Following are suggestions for developing your promotional plan:

Professional assistance - contact all medical professionals who might help you spread the word, particularly those with whom you are familiar. They are more apt to give someone your business card if they know you.

Define your market Research contacts Consider sending out press releases, brochures, newsletters, business cards Contact national organizations Use internet resources.

Acknowledgments:

Parent to Parent of Pennsylvania, National Spinal cord Injury Association, Support/Path.Com, Self-Help Network, 4Non-Profit Organization

International regions

A NEW CONCEPT AND UNDERTAKING FOR THE FOUNDATION

The past year was perhaps the busiest ever for the Board of Directors of The Foundation, with many matters coming before the Board for policy decisions and votes. One of the most important issues brought to the attention of the Board by one of its members was the need for The Foundation to become more inclusive of people from outside of the United States in its activities. Although The Foundation has always had approximately one-quarter of its membership from outside of the U.S., only one of its meetings to date has been outside of the U.S., and there are fewer people outside of the U.S. with internet access and availability of information from The Foundation's web sites. It was therefore decided by the Board to elect Regional Directors who would report to the Executive Director about activities in their regions, and to find ways for The Foundation to assist in the dissemination of information and the establishment of as many activities as possible in each region. A decision was also made to schedule additional meetings outside of the U.S. in the near future. Future meetings in Europe and Australia are being planned for 2006. The Regional Directors will link The Foundation to support groups and professional associations in the five international regions to facilitate a bi-directional flow of information to as many venues as possible. The Regional Directors were nominated by the Board and elected at the Business Meeting.

They are:

- Pacific Rim (Australia and Asia): Stephen Russell, LL. B., Brisbane, Queensland, Australia

- Central and South America: Antonio Ysunza, M.D., Mexico City
- Europe, Continent: Stephan Eliez, M.D., Geneva, Switzerland
- Europe, British Isles and Ireland: Ahmad Al-Khattat, M. B.B.Ch., B.Sc.(Hons), and Julie Squair
- Middle East: Doron Gothelf, M.D., Tel Aviv, Israel

We are hoping that we can attract interest from other regions, as well and add additional regional directors to participate in Foundation activities.

The Tenth Annual International Meeting of The Velo-Cardio-Facial Syndrome Educational Foundation, Inc. and the Fourth International Conference for 22q11.2 Deletions will be held from July 23-25, 2004 in Atlanta at the Colony Square Hotel and Conference Center. This meeting is being sponsored jointly by The Velo-Cardio-Facial Syndrome Educational Foundation, Inc., the Fourth International 22q11.2 Deletion Conference, and Children's Healthcare of Atlanta. For more information contact Gail Klein, BSN, RN, Program Coordinator, (404-785-7841, gail.klein@choa.org) or Karen J. Golding-Kushner, Ph.D., Executive Director of the VCFSEF (<http://www.vcfsef.org>, 732-238-8803 or toll-free 1-866-VCFSEF5).

Say Good Bye *continued. . .*

reluctant to participate in the organization if the source of information was coming from a place that had a vested interest in treating patients. Lay people, especially those who were parents of children with VCFS, might be reluctant to join this organization if they were patients at other institutions. Both Dr. Kushner and I were present at that meeting, as were our first two Presidents, Joe Abruzzi and Harry Keleshian, among others. Although most of us were from the larger New York metropolitan area, we realized that this new group could only be successful if we opened up to an international membership. We agreed to draft a set of by-laws, and to launch The Foundation with a meeting that next spring. All of us made as many contacts as we could with friends and colleagues to recruit members. We formed a Board of Direc-

tors from our founding members, accepted the by-laws, and held elections, and I got the brass ring of the Executive Director's position. Our by-laws set term limits for each office in order to maximize the number of people who could take leadership roles. For example, the President is always a lay member, and the office is held for one year with no chance for re-election. Our Secretary-Treasurer is also a lay member, and holds office for three years with two additional terms allowable if re-elected. The office of Executive Director is held for four years with the possibility of two re-elections. Each of our six Board members (three lay, three professional) holds office for three years with two members, one lay and one professional, cycling off each year with no re-election

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Say Good Bye *continued. . .*

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possible. I was re-elected as Executive Director four years ago, and I was eligible for one more term, but for reasons I will explain later, I decided against seeking an additional four years in office.

With an initial total membership of approximately 100, we held our first meeting in the Bronx with over 150 in attendance, and the late Dr. Tony Lipson came from Australia to be our first guest speaker. The meeting was a huge success and membership broadened to several hundred over that next year. Our second meeting was also held in the Bronx with a strong program and close to 200 registrants from the U.S., Australia, and Europe. At our business meeting and Board of Directors meeting, we decided that, if we were going to be true to our mission, we would need to have the meeting leave the Bronx (my home base) and move to different locations each year. That way, the meeting would not be perceived as the property of one location or one institution, and we would be able to reach audiences in many locales. In following years, we met in California at Stanford, in Boston at Children's Hospital, and in Milwaukee at Children's Hospital of Wisconsin.

We continued to have strong registrations of over 200 people at each of those meetings.

We then decided that it was time to assert our independence even more by moving the meeting away from hospitals and universities, to a hotel. We did that in Baltimore and had over 300 people in attendance, and followed the next year with a strong showing in Florida. Last year, we took the next bold step and held the meeting outside of the U.S. for the first time last year and were rewarded with a huge crowd in Northampton, U.K. Over 260 people attended our meeting in San Diego this past August.

We have published many Newsletters, established a web site, and we have sent out materials to lay people and professionals alike. Over the nine years of annual meetings, we have reached well over 2500 people, and our membership is similarly in the thousands. Our web site had tens of thousands of hits. Our membership spreads across every continent and includes professionals and lay members from over 25 nations. This year, The Foundation elected Regional Directors for Europe, the Middle East, the Pacific Rim (Asia and Australia), and Central and South America. These Regional Directors (see the announcement in this issue) are all committed to The Foundation's mission and will utilize the resources of the Foundation to educate po-

tential billions of people. None of these Regional Directors, Ahmad Al-Khattat and Julie Squair (British Isles and Ireland), Stephan Eliez (European Continent), Doron Gothelf (Middle East), Stephen Russell (Pacific Rim) or Antonio Ysunza (Central and South America) were members of The Foundation at its founding in 1994. They are all, in a sense, products of The Foundation's mission, and all have contributed enormously to its mission.

So, the question is why step down now Executive Director when The Foundation is reaching heights that none of its founding members could have envisioned in 1994? One reason is that it is not healthy for an organization to be too closely identified with a single person. From time to time I have heard people who are not familiar with The Foundation refer to it as "Bob Shprintzen's group" or something similar. This really annoys me because it flies in the face of our founding purpose for The Foundation, but it does point out the need for new leadership. Another reason is that fresh ideas must always be infused into organizations to keep them alive and growing. I have truly given my all to The Foundation, and sometimes one gets so focused on their approach to how things should be that it is possible to ignore new ideas not originating with the leader. There are so many members of The Foundation who have so much to offer and they must be given a chance.

"So, the question is why step down now as Executive Director ..."

There are so many people to thank that I am reluctant to do so for fear of offending a single one of them. These generous souls have given so much to the Foundation without seeking or receiving the credit they deserve, but they, like me, have asked for nothing more than the satisfaction of serving a noble cause. I am not talking about just a few people, but many from all over the world's map. To my friends who are reading this, you know who you are, and you know I mean it when I offer my gratitude.

I would like to emphasize that I am not so much stepping down (this implies removing myself from The Foundation) so much as stepping aside to make room for others to share the pleasure I have had for the past nine years. I will remain in an advisory capacity to Dr. Kushner for a brief period of time until she has a firm grip on the day-to-day operation of The Foundation. She and the Board have already assigned me committee work and new challenges that I relish. I will continue to attend meetings, and I will continue to work to assure that The Foundation can fulfill its mission. I will turn more of my attention to my job at Upstate Medical University, and with any luck, I will be able to spend a bit more time with my family, but I will never turn my back on The Foundation nor deprive it of my time if it will be of benefit. Thank you all for allowing me the privilege of serving you.

VELO CARDIO FACIAL SYNDROME EDUCATIONAL FOUNDATION, INC

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

Email: kgkushner@vcfsef.org

PO Box 874

Milltown, New Jersey 08850

Phone: 732-238-8803

Toll Free: 866-VCFSEF5 (866-823-7335)

Initial Inquiry: info@vcfsef.org

General Email: vcfs@vcfsef.org

Web Site: <http://www.vcfsef.org>

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Your VCFS information source

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fessors, and, after receiving my MA, returned to New York. I started working at Montefiore Medical Center in 1978, just when the group at the hospital's Center for Craniofacial Disorders published its first article on VCFS, and had the opportunity to examine the language skills of a group of children with the syndrome carefully, leading to the first publication on language skills in VCFS. I spent most of the next 17 years there, eventually becoming Clinical Director of the Center for Craniofacial Disorders. Collaborating with professionals in various medical, surgical, and dental disciplines, and with parents, teachers, and other community specialists has been a key part of my own professional existence from the beginning.

I left Montefiore for several years during which time my husband and I lived in Israel. There, I started a speech therapy program at Shaare Zedek Medical Center in Jerusalem, and coordinated their Cleft Palate Team. I performed Israel's first multi-view videofluoroscopic examinations of velopharyngeal insufficiency and received invitations to speak around the country on cleft palate speech, and VCFS. It was very exciting, even though few if any children there had been diagnosed with VCFS at that time, and it was long before we knew that it was the 22q11.2 deletion that caused the disorder.

My husband and I returned to New York in 1985 and I returned part-time to Montefiore while finishing advanced study at the Graduate School and University Center of City University in New York. I received my Ph.D. in Speech Science after completing a dissertation entitled "Craniofacial Morphology and Velopharyngeal Physiology in Four Syndromes of Clefting." One of those syndromes, of course, was VCFS.

I left Montefiore in 1995 and since that time have maintained a private practice while holding other speech path jobs, including work in Early Intervention programs, public schools, and nursing homes. I was on faculty at Kean University in New Jersey, where I taught graduate and undergraduate courses in speech-language pathology. However,

I found that I did not have enough professional time to spend doing what I love most: working with babies, children, and adults with speech problems due to clefts, syndromes, and VPI, researching ways to do it even more effectively and efficiently, and training parents and SLPs to do it also.

Throughout my career, my clinical and research interests have centered on understanding the speech mechanism and the anatomic structures that influence how we speak, what goes wrong, and how we fix it. Most of my presentations and publications have addressed speech and language associated with syndromes of cleft palate, especially VCFS. It seemed fortuitous that the Foundation nominating committee approached me about becoming Executive Director, just when I had decided to leave the University so I would have more time to spend on my specialty!

I am certain that members of the Foundation join me in thanking Dr. Shprintzen for founding and leading this incredible Foundation. The VCFSEF was born of his vision and dreams, and he made them a reality. He grew the Foundation from a nucleus of a few people to an international presence, encouraging interested professionals and non-professionals to participate in helping it grow along the way. He devoted his time, intellect, spirit, and energy to the mission of this organization, often at the expense of time from his family and job. He has been quiet about the fact that he was eligible for one additional four-year term in office as Executive Director. He declined because he thought it was better for the Foundation to have an identity that was independent of him and his place of employment. Many people tried to persuade him to wait another four years, but he insisted that this was important for the Foundation. That attitude is so typical of his generosity and selflessness. It is very difficult to follow a person of his skill and quality, as I have known for the last 30 years. Dr. Shprintzen has promised to continue to serve the Foundation in a variety of ways, and I have already put him to work.

I am honored to have been elected to this position and look forward to working with all of you- professionals, families, and our new Regional Directors- to improve the lives of individuals touched by VCFS.

As you have already noticed, we are introducing some new features into our newsletter. Plans are underway for our next annual meeting, which will be in Atlanta in July 2004. The new contact information for the Foundation is elsewhere in this newsletter and on the website. Please feel free to write, email, or call me to say hello, or if you have any ideas about new ways in which the Foundation can fulfill its mission: to educate the public about velo-cardio-facial syndrome. I look forward to hearing from you.

In the next issue:

Meet the Regional Directors

&

"The Art of Negotiating", by Linda D'Antonio