

# VCFSEF NEWS

Volume 8, Issue 3  
December 2002

## Announcing the 9<sup>th</sup> Annual Meeting of The Velo-Cardio-Facial Syndrome, Inc.

**San Diego Marriott Mission Valley  
San Diego, CA, August 1 – 3, 2003**

The 9<sup>th</sup> Annual Meeting of the VCFSEF will be held in beautiful San Diego, CA from Friday, August 1 through Sunday August 3 at the San Diego Marriott Mission Valley Hotel. The hotel is within minutes of many attractions, including Old Town, Sea World, the Gas lamp District, beaches, and the San Diego Zoo. The Mexican border and Tijuana are within easy reach, as is the Wild Animal Park. We have negotiated an excellent rate of \$109 (U.S.) for single and double rooms, \$119 for triples, and \$129 for four people in the same room. As usual, we will have our annual dinner following the business meeting on Friday night, August 1st. Continental breakfast will be included each morning for meeting registrants in the meeting room.

Reservations can be made by calling the hotel directly at 619-692-3800 or by calling Marriott Hotels at 800-228-9290. Be sure to mention the Foundation meeting when you make your reservation in order to receive these special rates. Reservations at the hotel should be made before July 1, 2003 in order to receive these special room rates. Additional announcements regarding meet-

*Reservations at the hotel should be made before July 1, 2003 in order to receive these special room rates .*

ing events, the program, and registration information will be sent shortly. An abstract form is included in this newsletter for members who would like to present at the meeting. For Professional Members, you may present a paper (15 minute format) or a brief clinical case report (5 minutes). If you have clinical or treatment seminars that would require 30 minutes, several slots will be made available in the program. For Lay Members, we are soliciting presentations in the areas of Sharing the Good Times, and also presentations involving issues you think both professional and lay members need to know about in relation to the management of children with VCFS. We encourage your participation in the meeting, and as always, we will leave plenty of time for interaction, questions, and discussions. Clinics will also be held as in years past, and these will be announced in the next mailing with the registration forms.

Thanks to our President, Pam Hunter, for planning this opportunity to get together in beautiful Southern California.

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### Conference Highlights

- San Diego, California, August 1st-3rd
- Abstract Form for submissions on page 7.
- The hotel is just minutes from many attractions, including Old Town, Sea World, the Gaslamp District, beaches and San Diego Zoo.

## Reflections on a Writing Life

**by Apryl Fox, age 20**



From childhood's hour, I relished literature of all kinds: classics, poetry, fantasy, horror. It was not long, however, before I realized my real talents lay in the written word. Even after I was diagnosed with VCFS at just three-years-old, I began to write novels, poems, and stories by the time I was twelve-years-old. By then I was reading the works of Shakespeare, Dickens, and even Tolstoy's

"War and Peace."

Now I'm twenty-years-old. I have completed five novels, and have written over 900 poems. I am currently working on a fantasy series of eight books, two science fiction novels, and a realistic adult fiction novel called "Cattle Country." I know how hard it is to get published, especially with someone who has a disability. Our voice is just as important as anyone else's, and what better way to accomplish that than to have a creative newsletter of our own?

When a person finally declares himself a Poet, a peaceful calm falls over his life until he gets an Idea, for the need to get the Idea down on paper is so overpowering that the feverish passion nearly consumes him. He cannot sleep. He cannot eat. Functioning in normal society is almost impossible, the words swimming in his brain so precious he fears they will be lost. Then, he is not a Poet, but a creator.

The very best of Poets can take something simple and give it beauty: a rose, a cloud, a blade of grass. It is no wonder why the works of William Blake, Emily Dickinson, and many other poets chose Nature as their subjects in their creations, and it was not long before the likes of Henry David Thoreau took it one step further, living a simplistic life in a cabin just outside of Concord, Mass. He detailed these simple wonders in a journal simply titled "Walden."

Poems are often written in a simple format of verse, free verse (poems that do not rhyme), and sonnets, which are one of the oldest forms of rhyme since Shakespeare's "Shall I Compare Thee To a Summer's Day." A sonnet consists of twelve to fourteen lines of rhyming verse, usually in this pattern: abab. Perhaps William Shakespeare's work has survived for so long because, he did not write just for his readers, but for the common man.

It is important that our voices be heard, for the Muse can manifest itself at anytime, anywhere, and in anyone – as long as one is willing to pick up a pen.

**Editor's note:** Ms. Fox's poems can be viewed at her website: [www.angelfire.com/co4/carlmil17/poemsbyapryl.html](http://www.angelfire.com/co4/carlmil17/poemsbyapryl.html). I have taken the liberty of selecting a few of her poems from for our readers' pleasure. Apryl has expressed an interest in organizing a publication of poems and short stories by persons with VCFS. If you are interested, contact Apryl at [girlinpurplerain@juno.com](mailto:girlinpurplerain@juno.com).

### Nothing Endures but Change

Seasons come and go;  
dewdrops melt to tears,  
and the laughter of the wind fades to  
nothing more than

a soft whisper as it caresses the  
skeleton trees of autumn,  
bare and brittle,  
they sleep until the rivers sparkle  
against the diamond sunlight  
of change.



### Parody

Sometimes there are unfinished poems  
That sit on a desk, gathering dust.

Patiently – the unfinished poems wait while  
the old poet smiles  
And mutters to himself in the cold, empty house

## VCFS Teen Support Groups in Boston!

Children's Hospital in Boston is planning a set of Teen Support Groups for young people with 22q11 deletion (VCFS). Groups for boys ages 12-15 and 16-22, and girls age 12-15 and 16-22. Tuesday nights from 6:00 p.m. to 7:30 p.m. depending on interest. **Group size limited** to 8 people each.

If you are interested in this program, call **Johanna Black @ 617-355-5429** for details. Conducted by: Joseph E. Nyre, Ph.D. (*Child Psychologist, Dept. of Psychiatry*), and Dita Obler, M.S. (*Genetic Counselor, Dept. of Cardiology*)

## Meetings Around the World

This past July, the VCFS Educational Foundation, Inc. held its 8<sup>th</sup> Annual Meeting in Northampton, United Kingdom, its first meeting ever outside of the United States. The meeting was an enormous success with over 270 registrants converging on the meeting site in Great Britain from Europe, Asia, Australia, and North America. The local arrangements committee headed by Julie Squair, Bob Squair, and Ahmad Al-Khattat were tireless in their efforts to keep the registrants happy. The presentations at the meeting were excellent and there was an enormous amount of interaction between the faculty and the registrants. Speech, feeding, and leg pain clinics were held by Karen J. Golding-Kushner, Susan Marks, Robert Beecher, Natalie Havkin, and Ahmad Al-Khattat. The meeting has pushed the total attendance of the Foundation's annual meetings to over 2,000 since 1994. The Foundation is looking forward to its 9<sup>th</sup> Annual Meeting in San Diego, CA, August 1 – 3, 2003, its 10<sup>th</sup> annual meeting in Atlanta, GA in 2004, and Syracuse, NY in 2005.



Stephen Russell introducing the program at the first meeting of the VCFS Foundation of Queensland, November 2, 2002.

### The Velo-Cardio-Facial Syndrome Foundation of Queensland

The VCFS Foundation of Queensland (Australia) held its inaugural meeting in Brisbane October 31 through November 2, 2002. The meeting was attended by families and professionals from all of the Australia states, as well as New Zealand. There were over 145 registrants. The meeting was only the second of its type held in Australia; the first held many years ago under the guidance of the late Dr Tony Lipson, of Sydney, Australia. The international faculty included Robert Shprintzen,



Mr. and Mrs. Raymond Tanner at the Gala Ball. Raymond was one of the speakers at the meeting.

Karen Golding-Kushner, Donna Landsman, Stephan Eliez, and Bronwyn Glaser. Faculty from Australia participated in the meeting, as well. The great news from the meeting is that VCFS delegates from all of the Australian states have agreed on the establishment of a national Australian VCFS Foundation. This body has now been incorporated as a company under Australian law. Its members are the various State and Territory VCFS Foundations or Associa-

tions. One of the immediate benefits of the conference was that it provided the impetus for some of the State bodies to incorporate in a more formal way, to permit them to join the Australian Foundation. The Australian Foundation is aiming first to become more efficient in pooling and disseminating information. The board will be discussing such things as the introduction of a national newsletter, national meetings, website(s), resource library, and conferences. At present, the Australian Foundation may be contacted through the State Foundation for Queensland at its web site, [www.vcfs.com.au](http://www.vcfs.com.au), or by email at [mail@vcfs.com.au](mailto:mail@vcfs.com.au)

### The Third International Deletion 22q11.2 Meeting

Ospedale Pediatrico Bambino Gesù, Rome, Italy, was the venue for this meeting of scientists from around the world who presented their work this past June 7 and 8. Presenters and guests, too numerous to mention in this space, came from Europe, North America, South America, and Asia and were treated wonderfully by their hosts in Rome, including Bruno Marino, Alberto Ugazio, Bruno Dallapiccola, and Laria Cristina DiGilio. Honored guest Angelo DiGeorge gave the opening lecture. There were over 100 registrants in attendance.



Donna and Jeff Landsman at the Gala Ball of the Velo-Cardio-Facial Syndrome Foundation of Queensland on November 3, 2002



Bronwyn Glaser, and Stephan and Sommeli Eliez, all of Geneva, Switzerland, at the Gala Ball.



Stephen Russell, Founding Member of the VCFS Foundation of Queensland with Karen Golding-Kushner, Ph.D., one of the guest speakers at the meeting.

## Language Impairments and School Success

**Nancy J. Scherer, Ph.D.**

*Professor, Department of Communicative Disorders  
East Tennessee State University*

*This article is the third in a three-part series on speech and language problems of children with VCFS. This article discusses issues in working with school-aged children.*

As children begin school they encounter many new social and learning experiences. Of the many requisite skills for school entrance, speech and language performance is one of the predominant predictors of school success. Children with Velocardiofacial syndrome (VCFS) often enter school with an early history of speech and language delays and suspect palatal function and later go on to experience learning difficulties in school. What do we know about the impact of these early delays on school performance?

Some studies have been conducted on the speech and language development of children with VCFS during the school years (Shprintzen, Goldberg, Lewin, Sidoti, Berkman, Argamaso & Young, 1978; Golding-Kushner, Weller, & Shprintzen, 1985; Moss, Batshaw, Solot, Gerdes, 1999; D'Antonio, Scherer, Miller, Kalbfleisch & Bartley, 2001). These studies found the following:

- Speech development gradually improves through the school years
- Receptive and expressive language delays continue from preschool years through school ages

Many children with VCFS experience severe speech impairments and palatal dysfunction during toddler and preschool ages. These deficits often become the focus of intense speech therapy and/or surgical interventions. By school age many children with early speech impairments are improving their speech production, although still requiring speech therapy.

At the same time receptive and expressive language performance delays persist into school age and may not have been addressed in prior speech therapy. These delays interact with the initiation of academic instruction and have a far-reaching influence on the learning process.

A recent study that compared the language performance of children with VCFS with children having specific language impairment showed that the 2 groups were more similar than they were different in their performance (Swillen, Deviendt, Shesquiere, & Fryns, 2001). This means that children with VCFS appear to have language delays much like other chil-

dren with Specific Language Impairment (SLI) who do not have VCFS. This finding is important because, while there is limited information on the language disabilities of school-aged children with VCFS, there is considerable literature on the developmental progression of language impairment and its relation to academic performance that may be relevant for children with VCFS.

Studies of children with SLI have shown that these children experience difficulty with the following activities:

- Phonological awareness skills
- Sound-letter correspondence,
- Rapid naming tasks
- Delayed understanding of complex directions
- Spelling
- Reading comprehension
- Math concepts

How does language impairment contribute to academic learning? For school-aged children, language impairment undermines the foundation for academic learning. This influence may be pervasive; in which case, the child does not have success in broad areas of academic performance. Or the influence may be subtle, in which case the child learns some skills but not others so that their achievement is uneven.

Beyond the impact on academic learning, language impairment influences the ability to carry on a conversation that is key to social interaction with peers, teachers and families. However, storytelling abilities are also important for academic learning. Narration, or the ability to tell a story, develops during the preschool and early school years. Narrative abilities are used in many classroom activities from describing a movie to a book report. They require that the child use and understand vocabulary and sentence grammar but also that they sequence their description adequately and give sufficient information to the listener so that the story makes sense. In addition to conversational and narrative language use, children with language impairments have difficulty understanding language presented to them. If a child has difficulty understanding the vocabulary and sentence structure used by the teacher when explaining concepts in the classroom, then they will be at a disadvantage in learning a new concept. This becomes particularly important when the child is learning a new skill, such as reading or spelling. Additionally, for children beyond third grade, reading becomes a primary mode of acquiring new information. As such, deficits in language contribute to impairments in reading comprehension, which have long lasting affects on academic learning. While

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**...children with VCFS appear to have language delays much like other children with Specific Language Impairment (SLI) who do not have VCFS. This finding is important . .**

## Language Impairments continued...

(Continued from page 4)

additional studies of language impairment in school-aged children with VCFS are warranted, there are some recommendations for parents to consider. First, although your child may be enrolled in speech therapy, it is important that their language development be assessed routinely during school age. A comprehensive language assessment should include age appropriate standardized tests of language development that compare your child's receptive and expressive language to age norms, but more importantly, the assessment should include procedures that assess understanding and use of language in conversation and in book-reading or other tasks that mirror functional activities. Second, intervention should then address language deficits within these functionally appropriate contexts. Intervention goals can use content from academic subjects to enhance the connection between language intervention and academic performance. Your child's speech-language pathologist can provide guidance regarding application of language intervention programs to your child's own unique needs.

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**A**t the Foundation . . . the winter we've missed for the past two years has **finally found us**. The weather experts tell us that in another couple of inches our snowfall will exceed last years total (before this last two feet we had 40 inches). Skiers in Colorado are wishing they were New Yorkers !

**We remain energized** at the Foundation. This year we upgraded our web site this year, and more IS pending. We plan a revised PDF format **information packet** that combines much of our previously published information. The PDF file can contain a *lot* of information, is small enough to email or download from the web, and you can read it at your computer or print out just the parts you need on your printer.

Beginning with THIS issue, the newsletter will be easier to publish. Thanks to **Microsoft Publisher**, I now have a **master template** so I can pretty much "drag and drop" information into it and get it formatted quickly. **Now**, we just need articles from all those busy contributors around the world. And, in the near future, hopefully we can get away from paper newsletters altogether, and save trees and postage — well...actually, it'll save *OUR trees and postage* — and let you print it out on your own paper (smile).

Finally, we plan an **OPT-IN** email system for our e-news updates to manage ever-changing email addresses. Since email is our fastest means of communication, out-of-date email addresses are our biggest enemy. Update your email address with us by sending an email to:

**kelvin@vcfsef.org**

**Subject:** Email Address, and include ONLY your name, postal address, and email address.

If you have any other questions or suggestions, send them to me at **kelvin@vcfsef.org** and I'll be happy to review it. In the meantime, I wish everyone a joyous holiday season, and the best of health, wealth, wisdom and happiness in the new year.

Have an **AWESOME** kinda day.

Kelvin P. Ringold  
Web Master—<http://www.vcfsef.org>.

P.S. In case you have some rodent problems, I put a small photo of myself at <http://www.vcfsef.org/kelvin.html>, and a little blurb about what I do at the Foundation. Print out the photo and put it around, and your rodent problems are over. **NO CHARGE!**

## How Does Brain Anatomy Affect Learning in Children with VCFS?

**Wendy R. Kates, Ph.D.**

Parents of children with VCFS are continually seeking information about the physical, developmental, and academic challenges that this syndrome poses for their children. One area of increasing interest to parents is brain development. Conference presentations in recent years have described ways in which the structural anatomy of the brain in VCFS children differs from that of typically developing children. But the link between brain and behavior is not always clear, and raises an important question: What do these scientific findings mean for my child? How will these differences in brain development affect my child's ability to learn? In this article I will address these questions by describing in more detail some of the research findings relating to brain differences between VCFS and typically developing children and then describe how those differences might affect learning and school performance. I will conclude by emphasizing the importance of appropriate educational interventions and experiences to the developing brain.

The development of magnetic resonance imaging (MRI) brain scans during the past 15 to 20 years has permitted physicians and scientists to study brain development without placing children at any medical risk. MRI is a safe and painless procedure that detects radio frequency waves within a magnetic field to produce high resolution, three-dimensional pictures of the human brain. Early studies of the anatomy of the brain in children with VCFS were *qualitative*, meaning that the scientists examined the brain scans of each child visually, but did not carry out quantitative measurements of the brain. Qualitative studies found that many children with VCFS exhibited small cysts in or near their ventricles (the cavities in the brain that contain cerebrospinal fluid), unusually bright spots in their brains, and relatively small cerebellum.

However, some of the differences between the brains of VCFS and typically developing children are too small or subtle to be detected by visual examination of the MRI scan. In order to detect these very subtle differences, scientists have also imported the images produced by the MRI scanner into computer software programs, and used those programs to measure specific regions of interest in each child's brain. Scientists who have applied these methods to the study of brain anatomy in VCFS have detected significant *quantitative* differences between the brains of children with VCFS and the brains of children who do not have the 22q11 deletion.

The brains of most children with VCFS are about 11 percent smaller than the brains of typically developing children who are similar in age. Everyone's brain is comprised of gray matter (the part of the brain that processes information), and white matter (the long cables through which information is transmitted from cell to cell throughout the brain and the rest of the nervous system). In most VCFS children, the gray matter in the total brain is about 7 percent smaller than the gray matter of typically developing children, and the white matter is about 15 percent smaller.

Since specific skills are linked to specific brain regions, physicians and scientists are also very interested in how the 22q11 deletion affects specific regions within the brains of VCFS children. If the deletion affected all regions within the brain equally, we would expect that the gray matter in each region would be about 7 percent smaller in VCFS children, and that the white matter in each region would be about 15 percent smaller. But this is not what we have found. Several specific brain regions in VCFS children are altered more than we would expect. This means that the 22q11 deletion affects some regions of the brain more than it affects others.

*“The brains of most children with VCFS are about 11 percent smaller than the brains of typically developing children ...”*

One important brain region that is altered in VCFS is the parietal lobe. Both gray and white matter in the parietal lobes of children with VCFS is reduced compared to typically developing children. Not surprisingly, the parietal lobe is linked to the performance of several academic tasks that are particularly difficult for children with VCFS. For example, the parietal lobe plays a major role in our understanding of visual-spatial relations, which is often challenging for children with VCFS. Difficulty in understanding visual-spatial relations is, in turn, linked to difficulty in mathematics, a very pointy thorn in the academic side of VCFS children. In order to understand exactly what is happening in the parietal lobes of VCFS children when they attempt math problems, we will have to do functional MRI studies, which measure changes in blood oxygen in the brain while a person is performing a task during the scan. However, gray matter and white matter reductions in the parietal lobe suggest that VCFS children have difficulty in both the processing and the transmitting of mathematical information.

The parietal lobe is also linked to working memory. Working memory is the ability to hold information “on-line” while performing a task. For example, we have all asked for directions to a destination, and then tried to remember those directions as we are trying to reach our destination. We are using our

*(Continued on page 7)*

## Brain Anatomy continued. . .

*(Continued from page 6)*

working memory to keep the directions “in our head” as we are traveling. Many children with VCFS have difficulty with tasks that draw on working memory, and most likely, this difficulty is related in part to subtle alterations in the parietal lobe.

The frontal lobe of the brain is also involved in working memory. Interestingly, scientists have found that the gray matter of the frontal lobe appears to be “relatively preserved” in VCFS. This means that when compared to their same-age peers, VCFS children’s frontal lobe gray matter is not altered or reduced as much as the gray matter in other regions of their brains. This is promising, since the frontal lobe plays a major role in memory and also in many intellectual functions involving complex thought and problem solving. Scientists have observed, however, that the white matter in the frontal lobe of VCFS children is altered: children with VCFS have significantly less white matter in their frontal lobes than typically developing children. This alteration in white matter may make it more difficult for VCFS children to transmit information to the rest of the brain and to make the mental connections they need to make. The alteration in white matter may also contribute to the difficulties in abstract reasoning that have been noted in VCFS children as they develop.

Alterations in the hippocampus may contribute to the age-related increase in learning difficulties that have been noted among VCFS children. The hippocampus is located in the temporal lobe and plays a role in both long-term memory and learning. Scientists have found that the hippocampus in VCFS children is about 11 percent smaller than in typically developing children, which is what we would expect from the differences between the two groups in the size of the total brain. Unlike typically developing children, however, the size of the hippocampus is actually smaller in adolescents with VCFS than it is in younger children with this disorder. Although this suggests that the hippocampus in VCFS children may actually decrease as the child moves into adolescence, we need to follow the same children over time (in longitudinal studies) to confirm that the hippocampus truly decreases in size with age. If confirmed, this decrease might account for at least part of the age-related deterioration in academic performance that is sometimes noted in children with VCFS.

In addition to observing difficulties in math, working memory, long-term memory, and abstract reasoning, both parents and professionals have observed that children with VCFS are impaired in their abilities to maintain attention, get organized, and stay on task. Scientists believe that alterations in the connections between the frontal lobe and the caudate nucleus (a small anatomic structure in the middle of the brain) contrib-

ute to these difficulties. The caudate nucleus is altered in VCFS. It is very possible that the alterations in the caudate nucleus, along with the frontal lobe white matter, result in a disturbed “frontal-caudate network” in children with VCFS, and may contribute to the difficulties that VCFS children exhibit in attention, organization, and planning.

Parents will, no doubt, need to educate teaching professionals about the fact that the academic challenges VCFS children face are most likely related to subtle alterations in the structural anatomy of their brains. Hopefully, this information will support parents’ efforts to advocate for appropriate educational services for their children. But it will also be essential that educational professionals understand that the child’s brain, especially the white matter, continues to develop into adulthood, and is very responsive to environmental intervention. This is known as neuroplasticity, which is the lifelong ability of the brain to change as a result of new experiences and new learning. By providing VCFS children with well-designed and appropriate educational interventions and experiences, children can reorganize, increase and optimize the connections between brain cells throughout their brain.

We still have much to learn from studies of brain development and brain function in children with VCFS. Hopefully, the collaboration between parents and researchers that has permitted us to open this window of knowledge will continue, so that eventually we will fully understand the multiple links between the 22q11.2 deletion, brain anatomy and function, and academic development.

*“ Parents will, no doubt, need to educate teaching professionals . . . ”*

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## Memories from Northampton, England

### Julie Squair from VCFSUK sends:

“Thanks to everyone who pulled together at the last minute to make the meeting as wonderful as it was. It was pretty unbelievable that a group of people from different parts of the world could just “get together” like that and make it happen. They must have been jetlagged too! I would particularly like to thank **Nicky Daniels** of UCN who not only helped put the whole thing together but organised the creche and took a huge group of children swimming every morning. **The Moat House Hotel** were fantastic too and were there for every tiny thing we needed or wanted. **My Mam (Hazel)** missed all the talks as she was busy working her socks off on the registration desk with **Beth**. She had spent the few days before the meeting trying to help me with copying and labels on the computer, as well as keeping the children under control. **Audrey Smith** is a grandmother from the Isle of Man who came to the meeting with her daughter and granddaughter (both with VCFS - Emma is the little girl in the photo on the left). She worked really hard all weekend selling raffle tickets and other goodies. She regularly supports the 22q11 Group with fundraising.”



Emma and Katie at Fun Night, 2002.



Keeping the energy levels in check.

### VCFSEF EDUCATIONAL FOUNDATION, INC

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Your VCFS information source. . .

### Current Foundation Officers:

Executive Director:	Robert J. Shprintzen
President:	Pamela Hunter
Sec.-Treasurer:	Lisa Jennings
Newsletter Editor:	Eileen Marrinan

### Board of Directors:

#### Lay Members:

Linda Opper  
 Nancy Robbins  
 Fred Berg

#### Professional Members:

Bob Beecher  
 Stephan Eliez  
 Wendy Kates



Julie Squair about to get the \*golden\* touch .



ABSTRACT FORM FOR ALL SUBMISSIONS  
Ninth Annual Conference, August 1—3, 2003, San Diego Marriott Mission Valley  
The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.

TITLE: \_\_\_\_\_

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

TYPE OF PRESENTATION (*check appropriate category*):

- Professional paper (15 min)
- Professional Seminar (30 min)
- Brief Clinical Report (5 min)
- Lay Presentation: Sharing Good Times
- What We Need to Know

ADDRESS: \_\_\_\_\_

TELEPHONE: \_\_\_\_\_ FAX: \_\_\_\_\_ E-mail: \_\_\_\_\_

TIME REQUESTED FOR PRESENTATION (If different than above): \_\_\_\_\_

**AUDIOVISUAL EQUIPMENT:** All presentations will be computer based, including slide shows (Powerpoint or Corel Presentation Software). Videos will also be computer based and can run on DVDs or video CDS using Microsoft Media Player, Real Player, Quick Time and similar video programs. If you cannot digitize your video, the Foundation will do it for you.

Type or print the abstract (*without title or authors*) in the space provided below. If sent by mail, submit **3 copies**, to be received by **May 15, 2003**. Mail to: *Dr. Robert J. Shprintzen, at: Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome, Upstate Medical University, 750 East Adams St, Jacobsen Hall #714, Syracuse, NY 13210 USA*. **Abstracts may also be faxed (1 copy) to 315-464-6598, or emailed to shprintr@upstate.edu**