VCFSEF Newsletter

Voice of the VCFS Educational Foundation, Inc. **Spring - April 1, 2000**

University Hospital, 750 E. Adams St, Jacobsen Hall Rm 708, Syracuse, NY 13210 Telephone: (315) 464-6590

2000 Annual Conference in July!!!

(Reprinted from Nov '99 newsletter)

The 6th Annual Meeting of ***The Velo-Cardio-Facial Syndrome Educational Foundation, Inc.*** will be held in Baltimore, Maryland, July 21 - 23, 2000, at the Best Western Hotel and Conference Center in Baltimore, a short distance from the fabulous Inner Harbor. Call (800) 633-9511 or (410)633-9500 for reservations. Rates are $95 per night per room *(for up to four people)*. Make this a wonderful opportunity to take in one of the nation's hottest tourist locations while attending the meeting. As usual, the meeting will begin Friday, July 21 at noon and conclude Sunday, July 23 at noon. An optional opening reception and dinner will be held in the hotel Friday night...always a great time with a few special surprises this year. Social functions for Saturday are also being planned.

An innovative program will be presented, but if you have any program suggestions, please forward them to the Foundation office by email, fax, or snail mail (addresses listed below). An abstract form is included in this issue, should you wish to submit a professional/scientific paper, lay presentation, seminar, etc. The deadline is May 1st. A preregistration form is also included.

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

Over the past five years, over 1,000 people have taken advantage of this meeting. This means that information has been spread successfully to people who previously may not have had access to it. Come and help us increase that number to new unprecedented heights. The success and life-blood of the Foundation is its membership, the personal contact it promotes, and the open exchange between lay members and professionals. If you have never attended a meeting, let the 2000 meeting be your first. If you have already attended, come back to renew friendships made in past years.

In addition to friendship and learning, this year we can give you crab cakes, the National Aquarium, The Maryland Science Center, Camden Yard, boats and more boats, great food, and tons of shopping by the water. For additional information, contact the Foundation office. ❖

In This Issue. . .

Call for Dues

Membership dues for the calendar year 2000 should be sent to the Foundation Office when you receive this newsletter, if you haven't done so previously. There is no increase in the dues structure of the Foundation. A single membership is $25, family membership, $30. Dues may be waived on written request to the Foundation Office.

Your dues support the Newsletter, the Foundation's Web Site, our annual meeting, and many other activities. Last year, dues were collected from *less than 50% of the membership*, but we continued to provide our materials to everyone on our mailing list. Please take the time to offer this small token of support for the Foundation. ❖

6th Annual VCFSEF Conference Preliminary Program Released

A portion of the preliminary program for the 6th Annual Meeting of the Velo-Cardio-Facial Syndrome Educational Foundation, Inc. has just been announced. In evaluating the requests of the membership of the Foundation -- now over 1500 strong -- we have included a variety of presentations, discussions, and clinics to cover all ages of individuals affected with VCFS. The international faculty consists of esteemed scientists and clinicians with both long and extensive experience with VCFS, including many of the most important contributions to the scientific literature on the disorder.

Opening the session will be a presentation by the Executive Director, Dr. Shprintzen, titled *From 1975 to 2000: What Progress Have We Made in Treating VCFS From Infancy to Adulthood?*

Returning to the meeting will be several presenters from previous years, who have presented cutting edge research that was only possible through the collaboration and cooperation provided by members of the Foundation, including:

Dr. Stephan Eliez, Department of Psychiatry, Stanford University School of Medicine (*Functional Magnetic Resonance Imaging of the Brain in VCFS*)

Dr. Bernice Morrow, Department of Molecular Genetics, Albert Einstein College of Medicine (*Molecular Genetics: Of Mice and Men*)

Donna Landsman (*Educating the Child and Adolescent with VCFS*) and

Dr. Ahmad Al-Khattat, Nene College, Northampton, England (*Treating Chronic Leg Pains in VCFS: A 3 Year Follow-up*). There will be a special emphasis on resolving the communicative impairment associated with VCFS. Of special note is the speech clinic to be held for several days where acknowledged experts in treating children with VCFS will evaluate as many cases as possible, and demonstrate techniques for speech therapy. Among the experts participating will be:

Karen Golding-Kushner, Ph.D. (East Brunswick, NJ)

Robert Shprintzen, Ph.D. (Upstate Medical University, Syracuse, NY)

Natalie Havkin, M.S. (Upstate Medical University, Syracuse, NY)

Eileen Marrinan, M.S. (Boston, MA), and

Susan Marks, M.S. (Children's Hospital of Wisconsin, Milwaukee).

This assembly of clinicians represents the broadest experience with VCFS possible with a collective experience of thousands of patients and many scientific publications.

Two presentations on speech will also be on the program: *Speech Therapy In VCFS: A Model for Professionals to Follow* (Karen J. Golding-Kushner, Ph.D.) and *Speech Therapy In VCFS: A Model for Parents to Follow* (Natalie Havkin, M.S.). These will be practical sessions outlining treatment plans for individuals of all ages.

Also, related to speech production, Dr. Scott Tatum of the Upstate Medical University will present data on his extensive experience with the surgical correction of hypernasal speech in VCFS (*Surgery for Speech: Special Considerations and Outcomes in VCFS*).

Two special sessions from local faculty members will highlight the dynamics of family life and some strategies for building self-esteem. Dr. John Walkup, Division of Child and Adolescent Psychiatry at Johns Hopkins, will address self-esteem and strategies for avoiding conflict at home (*Fostering Self Esteem in Your Child and Conflict Prevention in the Home*). A *Sibshop* will address the issue of how brothers and sisters react to their sibs with special needs (Addison Beck, Child Life Specialist, Mt. Washington Pediatric Hospital). Nadine O. Vogel, MBA, Founder and Director of S.N.A.P. (Special Needs Advocate for Parents) will discuss mechanisms for providing for the welfare of children with VCFS once they reach adulthood (*Planning for the Future of your Special Needs Child*).

Also on the program will be a new video production by Pam Holland and John Ackourney. Those who attended last year's meeting will recall the excellent video presented in Milwaukee.

Julie Cooper, our President and local arrangements guru, has scheduled some concurrent workshops to tackle practical matters including the Sibshop mentioned above. Another new idea to be presented in a workshop for a small additional fee will be how to address social skills in children with VCFS. A class will be scheduled to focus on improving etiquette, listening and speaking skills, body language and cues, maintaining eye contact, telephone skills, and how to introduce yourself when meeting someone new.

A session on how regional support groups play an important role in easing the way for new families with children who have VCFS is also planned. This is not the entire program...just a sampling. More scientific material is being added and several additional exciting guest speakers are anticipated once travel arrangements have been confirmed.

The Call for Papers and presentations is still open until April 14th and both scientific and lay presentations are expected, as are several more additions to the program. The Leg Pain Clinic held by Dr. Al-Khattat also returns to this year's meeting.

All of this -- including the clinics, daily continental breakfasts and afternoon refreshments – is available for only $50 (single registration), $70 for a family of 2, or $80 for 3 or more family members (see the preregistration form in this issue), and the *optional* Friday night dinner is only $30 per person.

Lastly, some scholarships for the meeting covering registration and the dinner, are still available by written request to the Foundation Office.

See you in Baltimore. ❖

Tid-bits:

1. New phone number and address for the VCFS/DiGeorge Family Support Network of Washington: POB 13316, Everett, WA. 98206, 1-888-259-VCFS.

2. Shelly Czopek would like to expand the outreach of their Rocky Mountain Region support group. If you live in any Rocky Mountain State including Colorado, Wyoming, Montana, and wish to be affiliated with this support group, please contact her as follows: Shelly Czopek, 1880 Eldorado Circle, Superior, CO 80027. (303) 494-8071, or via email at: NUTRIWHIZ@aol.com.❖

On VCFS Research

by: Deb Copenheaver

In many academic medical centers, patients and their families are often asked to participate in research studies. At this time there are several on-going studies involving VCFS. The following is information you should know that may help you in your decision regarding participation.

It is important to realize that a research study is different than a clinical trial. A clinical trial involves a new treatment that is often a drug therapy otherwise not available to the public. Research studies usually involve providing the researchers with information (in the form of blood samples, DNA samples or test results) so they can analyze data. **Research studies do not affect the quality of care you receive.** You may, however, receive examinations and/or diagnostic tests as part of the study.

Before you decide to participate in a research study, read and understand the informed consent form. Informed consent means the patient or guardian of an underage patient has been given information allowing them to understand what is involved in the study. Signing the form means that one has decided to participate. All research projects should provide participants with a consent form that (1) clearly states the purpose of the study, (2) explains what is involved in participation and (3) lists the potential risks and benefits of the study. Other factors you should consider include: how much time and/or cost there will be, where will any information gathered from the study and who will have access to it, and will participants be notified of any results/conclusions made from the study. Even after giving informed consent, a patient can withdraw from a study at any time for any reason.

Be aware that research often goes on for years and results are sometimes never achieved. You should keep the name of a contact person and how to reach them if you have questions or concerns in the future.

You should also explore your own personal reasons for wanting to participate. Most people participate in hopes that the research will lead to a cure, better treatment and to help others better understand the disorder. However, in many investigations, no such promises are made, nor can they be made. Research is often piece-meal. Many projects yield small results that point in a direction; that direction then leads to yet another research project. The final goal may not come with a single research project, but may take many smaller ones. In the case of VCFS, many readers of this Newsletter may have provided their DNA (usually with a blood sample) to one of several institutions that are engaged in research. The DNA is often stored so that as new answers in these smaller projects become available, the researchers can go back to these older samples to look for new results. It is possible that the results of such studies will never be disclosed to individual subjects. In other words, participation in such projects is for the greater good, not necessarily for individual advantage.

Sometime patients wish to gain more information from talking to researchers who have a special interest in their disorder or to have particular test or examinations performed. Research studies serve as a link between the patient and their families and the health professionals. Countless advances in understanding medical conditions have been made due to volunteers and these studies. ❖

FAQ's (Frequently Asked Questions)

FAQs 1 and 2 were presented in the last newsletter.

3. My child seems to be "behind", developmentally. Will he/she catch up?

Developmental delay is a common manifestation in children with VCFS, but it is variable with some children showing almost no early problems and others being quite delayed. The majority of children, however, tend to fall towards the outer limits of normal for most motor milestones. Specifically, data derived from the membership of the Educational Foundation shows that the average age for walking is closer to 15 or 16 months than 12 months (the average for the general population). The delay in motor milestones has many contributors, including the generalized hypotonia (low muscle tone) that is common in VCFS. Also contributing are factors such as congenital heart disease, multiple hospitalizations and operations, chronic illness, and other factors that can restrict a child's activity. However, some degree of delay is to be anticipated. That being said, the large majority of children with VCFS do go through several "spurts" of motor development, especially between 3 and 4 years of age that tend to narrow the differences between themselves and other children quite a bit. By school age, the majority of children with VCFS tend to perform close to the normal range in terms of motors skills, although they may always be a little more hypotonic or even "clutzier" than other kids. Severe motor impairment is very uncommon among children with VCFS. Speech and language milestones tend to be slightly more delayed, with the average age of onset of the first word at 19 months, but again this is very variable. However, the same spurt shown by children with VCFS in motor milestones also occurs with speech and language. It would seem that children with VCFS have their own developmental profile that differs from that of other children. In general, most show significant "catch-up" before their fourth birthday.

4. *What kind of learning issues can I expect? Do all VCFS kids have these challenges?*

To date, essentially all individuals with VCFS have shown some type of learning disorder. For the large majority of children with VCFS, specific learning disabilities become obvious by 7 or 8 years of age. Although mental retardation can occur in VCFS, the diagnosis of mental retardation is reserved for a very small percentage of cases. However, IQ scores have been noted to drop in children with VCFS, often between 7 and 10 years of age, although this is variable. A drop in IQ scores does not represent a loss of intellect. Rather, it reflects the specific type of learning flaws that children with VCFS have. Many IQ tests, particularly the Wechsler scales, depend heavily on language mediated problem solving and abstract logic. These are specifically the areas in which children with VCFS do the poorest. Difficulty with abstraction and problem solving tends to interfere most with mathematics and reading comprehension. Children with VCFS tend to do well early on with letter recognition and sounding out words for early rote reading. However, later on when they are asked to extract meaning from a paragraph or page, they have a great deal of difficulty. Concepts are difficult to grasp, even things as seemingly basic as "opposite" or "reverse." Therefore, learning is best done by repetition and breaking things down into the smallest concrete units.

5. *I can't seem to get school personnel to take me seriously. What can I do to get help for my child?*

It is always best to work with a school system, rather than against it. Unfortunately, people often tend to become confrontational when they are frustrated by lack of action. The first and best step is to know what the schools must provide under state education law and individual school system policy. Once this is understood, it is always best to find a friendly ear within the school hierarchy with whom

reasonable conversation is possible. Confine contacts to important issue (in other words, don't wear out your welcome) and work in concert with the people in the schools rather than being persistently contrary. It is often true that there is more than one alternative to success. Allow teachers to express themselves and then react to that expression with candor, but kindness. There is no surer way to have difficulty than by challenging people so that they become defensive. Finally, get the support of someone expert in dealing with VCFS and have them work with you, as well. If you are well armed with facts and experts, and the school is willing to work with you, the outcome will be positive.

6. ***Where is the best place for me to get medical care for my child? Should we visit a VCFS clinic?***
This is really one of the most difficult questions to answer. As is true with many disorders that have only recently been discovered, there may not be a large number of people available with enormous experience or expertise. This is, in fact, the very reason for the formation of the VCFS Educational Foundation. It is possible to call or email the Foundation and ask if there are Professional Members located at a local facility. Although the Foundation does not endorse the skills or expertise of specific individuals, their membership in the Foundation at least speaks to their interest. There are hundreds of Professional Members from many different disciplines located around the world. There are only a few specialty centers that deal exclusively with VCFS at present, and hopefully that number will expand. It is obviously not possible for everyone to visit one of these centers. In dealing with local doctors, it is always a good idea to be direct in asking questions about experience with VCFS. Use the Educational Foundation's web site to arm yourself with as much information as possible about the syndrome so you can ask intelligent questions. If you are not satisfied with the answers, then you always have the option of seeing someone else. As in the previous FAQ, try not to be confrontational. No one enjoys an interaction with someone who tries to put you on the defensive. This, in fact, works both ways. Don't be put on the defensive by your doctor, and don't put your doctor on the defensive.

7. ***Do all children with VCFS develop psychological and psychiatric problems? What can I do to avoid them?***
As is true with all clinical manifestations of genetic syndromes, it is rare for any single abnormality to be present in every case. It is also true that even when present, not all anomalies have the same degree of severity. The psychiatric studies that have been published until now have presented some conflicting information, but it is safe to say that the majority of individuals with VCFS have some behavioral disorders. In most of these cases, the manifestations are not very severe and often do not require medical management. The frequency of severe psychiatric problems is fairly low, probably under 20%, but this exact figure is not known. Part of the problem in psychiatric investigations is that the severity of psychiatric illness varies with age, typically becoming more apparent in adult life. However, enough adults with VCFS have been studied to know that the majority do not have severe mental illness.

8. ***When should I tell my child that he/she has VCFS?***
This is a very difficult question to answer because the timing of informing affected children is dependent on more than one factor. Age is certainly one factor, as is the child's ability to understand and grasp the significance of the diagnosis. Also important is the reason for telling the child, as well as the manner in which the explanation is offered. For example, even a very young child understands that when they have chicken pox, they get little bumps on their skin that itch a lot. However, they do not understand that chicken pox is caused by the varicella virus, that it may have severe consequences if the infection spreads to the central nervous system, and that as an adult, the disease has different and more severe manifestations. Their understanding of chicken pox is different from that of an adult. therefore, the child should not be told more than they can handle, and explanations need to be put in terms of what they can understand. Such explanations should not be confined to one day, but may need to progress in complexity as the child gets older. The explanations should also be guided at least in part by a qualified genetic counselor. It is most important that the genetic implications and recurrence risks be understood by the time the affected individual is of reproductive age.

9. ***What are the chances of my having another child with VCFS if I don't have it and my spouse doesn't have it? Should I have my other children tested?***
In the large majority of cases where a child has VCFS but the parents do not, the risk of another child in the family being affected is no greater than the risk for the general population; approximately 1 in 2,000. However, parents may have chromosomal rearrangements, such as a balanced translocation, that could alter that risk. However, this type of rearrangement would likely be discovered once a chromosome analysis (karyotype) was done for the affected child.

10. ***I have been told that my child has DiGeorge syndrome. Is that the same as VCFS? What about partial DiGeorge? Is that the same as a less severe case of VCFS?***
A well-known clinical geneticist, Dr. M. Michael Cohen, Jr., has often said that geneticists are more likely to share their toothbrushes than their terminology. For a variety of reasons, VCFS is also known by a number of other labels, including DiGeorge sequence, Shprintzen syndrome, Cayler cardiofacial syndrome, 22q deletion syndrome, conotruncal anomalies face syndrome (in Japan), and, unfortunately, CATCH 22. CATCH 22 should certainly be dropped from the list of acceptable labels because it is an attempt at humor (based on the late Joseph Heller's novel and black comedy, *CATCH22*). In the case of "DiGeorge," the name was applied after Dr. Angelo DiGeorge, an endocrinologist at St. Christopher's Hospital in Philadelphia at the time, described athymia (absence of the thymus gland) and hypoparathyroidism in several newborns. It has since been learned that many of these early cases had VCFS. DiGeorge sequence (not syndrome) is so designated because it represents an

etiologically nonspecific grouping of symptoms that have multiple causes. For example, athymia and hypoparathyroidism has been found in babies with fetal alcohol syndrome, individuals with Niikawa-Kuroki syndrome (also known as Kabuki syndrome), and in babies with rearrangements of other chromosomes besides chromosome 22. The DiGeorge sequence is found in a small percentage of babies with VCFS (see the data base at our web site). The majority of children with VCFS do not have DiGeorge sequence. However, the largest number of children with DiGeorge sequence do have VCFS. In fact, all babies with DiGeorge who have deletions at 22q11 have VCFS. The differences in clinical expression of the deletion represents a phenomenon encountered by geneticists all of the time, known as "variable expression." The differences in labels, therefore, sometimes represent different clinical expressions of the same disorder. For an article describing this situation in more detail, see *The Name Game*, an article from one our past Newsletters that is included on our web site.

11. If VCFS is as common as some people say, why don't I hear more about it?

As genetic disorders go, VCFS is a relatively recent addition to the pantheon of known syndromes. There is typically a delay between the first publication of a new disorder (in the case of VCFS, 1978) and its wide acceptance into medical practice. In addition, VCFS may not draw the same notice as disorders such as Down syndrome in large part because the children are not very stigmatized physically. Because the diagnosis is more difficult, especially in babies, it may go unnoticed for years. However, there has certainly been a recent surge in interest in VCFS and the progress in its study and recognition over the past 5 or 6 years has been little short of remarkable. ❖

More Tidbits..

In search of...Spanish speaking individuals (volunteers) willing to assist in proofing / preparing written materials in Spanish and/or to whom I can refer Spanish speaking individuals who need VCFS information. Please contact Kelvin via email at vcfsef@mail.upstate.edu or via postal mail at the foundation address listed on page one. Additionally, if you are aware of a Spanish speaking web site on VCFS, please let me know as soon as possible.

For The Conference:

The rooms at the Best Western will hold up to four people. If you're interested in sharing a room, contact Julie Cooper at 410-484-8319, or via e-mail: bcooper710@aol.com.

IMPORTANT: The special $95.00 room rate at Best Western is ONLY GUARANTEED UNTIL June 21st. So be sure to call (800) 633-9511 or (410)633-9500 and make your reservations early.

LIMO SERVICE to the Best Western can be procured from King Airport Vans(800)474-9988. The rate rate to/from the Best Western are $18 one way, and $34 round trip.

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There will be a 4-hour "Self Esteem Workshop" for siblings.... also a 1 hour $15.00 ❖

Recent VCFS-Related Publications

Atypical deletions suggest five 22q11.2 critical regions related to the DiGeorge/velo-cardio-facial syndrome. *Eur J Hum Genet* 1999Dec:7(8):903-9.

Alla P, Phillip N, Azulay JP, Attarian S and J Pouget. **Epilepsy in an adult with chromosome 22q11 micro-deletion.** (article in French) *Rev Neurol (Paris)* 1999Nov;155(11):967-70.

Baldini A. **DiGeorge syndrome: complex pathogenesis? Maybe, maybe not.** *Mol Med Today* 2000 Jan;6(1):12.

Barr CL, Wigg K, Malone M, Schachar R, Tannock R, Roberts W and JL Kennedy. **Linkage study of catechol-O-methyltransferase and attention deficit hyperactivity disorder.** *Am J Med Genet* 1999 Dec 15;88(6):710-3.

Borgmann S, Luhmer I, Arslan-Kirschner M, Kallfelz HC and J Schmidtke. **A search for chromosome 22q11.2 deletions in a series of 176 consecutively catherized patients with congential heart disease: no evidence for deletions in non-syndromic patients**. Eur J Pediatr 1999 Dec;158(12):958-63.

Chow LY, Garcia-Barcelo M, Wing YK and MM Waye. **Schizophrenia and hypocalcaemia: variable phenotype of deletion at chromosome 22q11**. Aust N Z J Psychiatry. 1999 Oct;33(5):760-2.

De Chaldee M, Laurent C, Thibaut F, Martinez M, Samolyk D, Petit M, Campion D and J Mallet. **Linkage disequilibrium on the COMT gene in French schizophrenics and controls**. Am J Med Genet 1999 Oct 15; 88(5):452-7.

Garabedian, M. **Hypocalemia and chromosome 22q11 microdeletion**. Genet Couns 1999;10(4):389-94.

Kimber, WL, et. al. **Deletion of 150 kb in the minimal DiGeorge/velocardiofacial syndrome critical region in mouse**. Hum Mol Genet 1999 Nov;8(12):2229-37.

Lichtner P, et al. **An HDR (hypoparathyroidism, deafness, renal dysplasia) syndrome locus maps distal to the DiGeorge syndrome region on 10p13/14**.

Loder N. **Unfinished sequence—the catch on 22**. Nature 1999 Dec 2;402(6761):448.

Murphy KC et al. **High rates of schizophrenia in adults with velo-cardio-facial syndrome**. Arch Gen Psyniatry 1999 Oct;56(10):940-5.

Novelli G, et al. **Individual haploinsufficient loci and the complex phenotype DiGeorge syndrome**. Mol Med Today 2000 Jan;6(1);10-1.

Novelli G et al. **UFD1L and CDC45L: a role in Di George syndrome and related phenotypes**? Trends Genet 1999 Jul;15(7):251-4.

Ravassard, P, et al. **ZNF74, a gene deleted in Di George syndrome , is expressed in human neural crest-derived tissues and foregut endoderm epithelia**. Genomics 1999 Nov 15;52(1):82-5.

Rodriguez Criado G, et al. **Familial deletion of 22q11.2**. Genet Couns 1999; 10(3):325-7.

Sergi C, et al. **CATCH 22 syndrome : report of 7 infants with follow-up data and review of the recent advancements in the genetic knowledge of the locus 22q11**. Patholgica 1999 Jun;91(3):166-72.

Srivastava D. **DiGeorge syndrome: an enigma in mice and men**. Mol Med Today 2000 Jan;6(1):13-4.

Tobias, ES, et al **Towards earlier diagnosis of 22q11 deletions**. Arch Dis Child 1999 Dec;81(6):513-4.

VCFS-Related Abstracts
from the American Society of Human Genetics Annual Meeting held in San Francisco, CA, October 1999

Baldini A, et al. Haploinsufficiency of Genes from the DiGeorge Syndrome Region Causes Heart Defects in Mice.

Edelmann L, et al. A common molecular basis for rearrangement disorders on chromosome 22q11.

Hsieh PC, et al. Creating a mouse model for DiGeorge (DGS)/Velocardiofacial Syndromes.

Kucherlapati RS, et al. Generating a mouse model for Velo-Cardio-Facial Syndrome (VCFS).

Lindsay EA. Embryonic recovery is the mechanism for reduced penetrance of congenital heart defects in mice deficient for the DiGeorge syndrome region.

Murphy KC, et al. High rates of schizophrenia in velo-cardio-facial syndrome.

Reish D, et al. Isolated palatal anomaly is not an indication to screen for 22q11 deletions.

Tharapel AT, et al. Clinical application of PRINS as an alternative to FISH in the diagnosis of Prader-Willi/Angelman and Di George sydnromes.

Vitelli F, et al. Ufd1l, a Candidate Gene for DiGeorge Syndrome, is Essential but not Haploinsudfficient in Mouse Embryogenesis.

PREREGISTRATION FORM

(Preregistration will be accepted until June 30, 2000)

Sixth Annual Meeting, July 21 - 23, 2000, Baltimore, MD

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, and send it with the preregistration, you will receive the member's registration fee

Accommodations: The entire meeting will be held at Baltimore's Best Western Hotel and Conference Center, 5 minutes from the Inner Harbor and its attractions. All rooms are $95 (rate per room, not per person), up to 4 people may share a room. Reservations should be made directly with the hotel. Call 800-633-9511, ask for reservations and mention you are attending the Velo-Cardio-Facial Syndrome Educational Foundation meeting. The hotel has a heated indoor pool, exercise facility, free parking, food court, and restaurant. Complimentary transportation is provided to the Inner Harbor.

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, c/o Dr. Robert J. Shprintzen, C.D.U., Jacobsen Hall 714, Upstate Medical University, 750 East Adams St., Syracuse, NY, 13210. Receipts will be available at the door.

FORM FOR ALL SUBMISSIONS

Sixth Anual Meeting, July 21-23, 2000
The Velo-Cardio-Facial Syndrome Educational Foundation

TITLE:

SUBMITTED BY (underline person presenting):

TYPE OF PRESENTATION (check appropriate category):

Professional paper ❑ Professional Seminar ❑ Clinical case presentation ❑
Lay Presentation: Sharing the Good Times ❑ Lay Presentation: Helpful Hints ❑Other (describe)

❑_____

ADDRESS: _____

TELEPHONE: _____ **FAX:** _____ **E-mail:** _____

TIME REQUESTED FOR PRESENTATION:

AUDIOVISUAL EQUIPMENT REQUIRED:

Type or print the abstract (without title or authors) in the space provided below. Submit 3 copies to be postmarked by May 1, 2000. **Mail to:** Dr. Robert J. Shprintzen, *Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome, Jacobsen Hall 704, State University of New York 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@mailbox.hscsyr.edu by May 1st, 2000.