

VCFSEF NEWS

Volume 8, Issue 2
November 2001

2002 Conference in Northampton England

The Foundation will hold its 8th annual meeting in Northampton, United Kingdom, July 26 through 28, 2002. This will be the first meeting of the Foundation to be held outside of the United States and we are anticipating an international audience that will allow participants to interact with many professional and lay members of the Foundation who have not had the opportunity to attend previous meetings. The program will be announced in part in the next Newsletter. A call for papers and information on local arrangements follows below. Come join us. Our meetings have attracted a total attendance of over 1500 people since 1994, thus fulfilling the mission of The Foundation to educate both professional and lay people about VCFS.



submission and suggestion for is included in this Newsletter. Additional forms will be available on The Foundation's web site at www.vcfsef.org, or by mail or email. A program outline will be published in our next Newsletter after the first of the year, but the final program will become available by

June 1. Although this may seem late to some, we have always tried to keep our program as current as possible, and we have therefore opted to allow late submissions. If you have program suggestions, please contact The Foundation at the earliest possible opportunity so we may have them reviewed by our Board and Program Committee. You may contact The Foundation by telephone (+315-464-6590), email (vcfsef@mail.upstate.edu), or fax (+315-464-5321).

Call for Papers: Submissions and program suggestions will be accepted until May 1. A

Editor's note

The two articles on the next page written by Nathan and Patsy Kanter, exemplify the familiar story of a rocky road to clarity that many families share. The citing of particular professionals, medical centers or schools in this newsletter must not be construed as an endorsement by the VCFSEF.

The take home message is clear: Professionals who are familiar with the medical

and educational issues often associated with VCFS best serve children and their families.

Once the nature of the learning disability is fully understood, both public and private schools can effectively make educational accommodations. Appreciation of each student's unique learning style can allow for educational success, such as Nathan is experiencing.

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Conference Highlights

- Northampton England, July 26-28, 2002
- Accommodations listed on page 7
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- Form for abstract submission and full info included.

My life as a success! by Nathan Kanter

Throughout my middle and high school career I was always behind other students. It would take me longer to finish tests; when I ran out of time and the class was over I had only finished half the test. However the half that I would finish would be correct. The other half I did not finish but knew was counted as wrong. The schools I have previously been to never gave me enough time to finish tests and other school related tasks. I would be up all hours of the night studying for exams and doing homework, which half the time would not be correct. Then everything changed. I was diagnosed with a non-verbal learning disability. Then later on I was diagnosed with VCFS (velo-cardio-facial syndrome).

After this major event had occurred in my life and things were finally starting to click together as to why I had been struggling in school, my parents hired an educational consultant. Her name is Leslie Goldberg. She works out of her home and specializes in finding boarding schools and colleges for kids with learning disabilities. She knew of a small school in Williston, Vermont called Pine Ridge School.

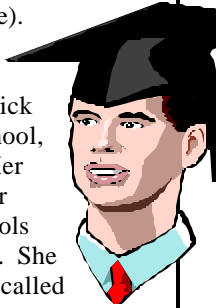
Pine Ridge is a very special place. It is a school where teachers including the headmaster and administrators are on a first name basis. They have a tutorial program where students work with tutors 55 minutes every day of the school week. This part of the program turned my life around like no other person or institution ever had before.

My tutor Dan Wolfe became a part of my educational career and without him I could not have graduated or done well in my classes at Pine Ridge. He worked with me on my strengths and weaknesses that we had set together. Till this day I owe much of my success at Pine Ridge to him.

Also at Pine Ridge they have a program that makes you socialize with other people. My social skills were already decent but became better as my life at Pine Ridge went on. By senior year I was all about socializing. I had a ton of friends and loved Vermont.

Without Pine Ridge I would never had made it past high school. The people there mean so much to me, and the fact that they put my goals in order, and made me challenge myself without fear is not describable. Even if I knew was going to fail it did not matter because I would eventually rebound and turn into an accomplishment and make it a learning experience of what not to do.

Currently I am enrolled at Curry College where I am studying and working hard. I am doing well and taking a regular course load as any other college student would. I am happy and learning.



A Mother's story

My name is Patsy Kanter. I am a Mom to Julie (24) and Nathan (20), wife to David and an elementary educational math consultant. This is the story of our son Nathan.

The History

When our second child, Nathan, was born he seemed like a normal baby. Shortly thereafter we learned that he had a VSD and a hernia. He had surgery for both by the age of one, and we were hopeful that all his difficulties were behind us. At this time and for sixteen years, we would have no idea he had VCFS.

At age 11, Nathan began to experience difficulty in school. At age 14, he developed significant nasality. It was not until then that we began to uncover that Nathan had VCFS.

Great efforts were made here in New Orleans to rectify Nathan's learning difficulties and his nasality, both of which had a marked impact on his self esteem and social being. Unsuccessful, we sought outside advice which led us to Boston Children's Hospital where they had a renowned developmental evaluation program.

David, Nathan and I went to Boston in the spring. After five hours of testing, the group recognized that Nathan had a pattern of anomalies symptomatic of VCFS. When shown the list of symptoms, he checked off in so many areas, that we and they were all but convinced of his condition.

The hospital sent us back to New Orleans for genetic testing, but made sure that we returned to Boston to have follow-up appointments with Dr. Gerald Cox and Ms. Eileen Marrinan. Nathan had a blood test back at home which confirmed the VCFS diagnosis. While Nathan was relieved to know that his learning problems were not his fault, David was dismayed and even a bit angry at the local medical community. Specifically, he found it difficult to accept that doctors failed to look at the whole child and his history rather than specific ailments as isolated events. He and I have developed the highest respect and admiration for the professionals at Boston Children's Hospital.

We returned to Boston, where Nathan was evaluated by Ms. Marrinan, Dr. Cox, and Dr. Mulliken. Within 16 months time, Nathan had palate surgery. It was not only medically successful, but its impact on Nate's social well being was immediate. During that period, we gained valuable knowledge and insight about his learning disabilities with the help of psychologist, Dr. Lisa Vervogli and were in pursuit of a new school for Nathan. We sought the help of educational consultants, and were most fortunate to find Lesley Goldberg. Through her help, we found the light at the end of the tunnel, Pine Ridge School.

I should stop here to tell you a little bit about Nathan, be-

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A Mother's story, continued

cause he is a very special person and his determination is what makes this story have a hopeful ending. Nathan is a wonderful human being, thoughtful, outgoing and very perceptive (a characteristic which is usually a shortcoming of VCFS children). He has learned never to give up. We have tried always to have high expectations of Nathan, but his expectations for himself far exceed ours.

His sister, Julie, has also been a wonderful role model and support for Nathan. Now in her third year of medical school, Julie seeks to help other children with a specialty in Pediatrics. She and Nathan are very close and he relies on her and she on him.

Pine Ridge School is really as Nathan describes it in his article. And his tutor, Dan Wolfe, was wonderful in sensing Nathan's desire to understand the world and seek education. The two of them were quite a team, working for three and half years to make sense of the world for Nathan.

Pine Ridge is small, with class sizes of 8-10. The days are well planned for the students and weekends offer a wealth of exciting adventures for the boarding students. Nathan's time was well planned for him and the structure helped him to make the most of it. Along with tutorial and social cognition classes (which Nathan describes), students take four academic subjects daily and PE.

Although Pine Ridge is far away from New Orleans, the staff always made Nathan feel safe and comfortable. He bonded with so many staff and students there. This made him realize his own strengths and develop wonderful self-confidence to succeed. Of course there were times when we all had to boost him up, but the school really helped him to become independent and self-reliant. In Nathan's senior year, he was encouraged by the school to have a car to further develop his sense of self-reliance and independence. This, too, became a source of strength for Nathan.

Nathan graduated in June of 2001, and he now attends Curry College where the PAL program supports his learning needs. He could never have made this step without the years at Pine Ridge and his determination.

My only advice is to never give up...keep looking for the light...David and I learned it from Nathan.

Patsy F. Kanter
patsyedc@aol.com

8th Annual Conference Fees (w/US \$ equivalents)

Single preregistration, member	£50.00	\$ 65.00
Family preregistration, 2 members (pls list names below)	£80.00	\$105.00
Single preregistration, non-member	£60.00	\$ 80.00
Family preregistration, 2 non-members (pls list names)	£90.00	\$120.00
Family preregistration, 3 or more members	£100.00	\$130.00
Family preregistration, 3 or more non-members (pls list names)	£120.00	\$160.00
Student member preregistration	£45.00	\$ 60.00
Student non-member preregistration	£55.00	\$ 75.00
Optional Friday Night Welcome Dinner	£22.00 per person	\$30.00

Please note: This year's registration fees have increased a little compared to last year, but registration includes lunch at the Moat House Hotel on the Saturday and a pastry lunch during registration on the Friday!

Defining and Addressing Speech and Language Problems in Children with VCFS-Ages 3 through 6

By: Susan Marks, MS, CCC
Speech/Language Pathologist
Manager of Speech/Language Pathology, Audiology and Otolaryngology
Children's Hospital of Wisconsin

This is the second in a series of three articles covering this topic. Since the first issue discussed children ages 0-3, this issue will focus on children from 3 to 6 years of age. The last article will discuss the school-aged child.

Despite many similarities, there is great variability in the performance of children in this 3 year to 6-year age group. This article describes the communication abilities of the child with VCFS in four communication areas: receptive language, expressive language, speech sound development and resonance.

Receptive language: Receptive language is the ability to understand what is expressed including verbal and nonverbal communication. As indicated in the previous newsletter, children with VCFS have better developed receptive language skills when compared to their speech production and expressive language abilities. (Scherer, D'Antonio et al. 1999) Of importance is that hearing, cognitive abilities and processing skills all impact language comprehension. Children with VCFS may present with variable deficits in these areas thus affecting receptive language skills. For a number of reasons including immune disorder or deficiency and palate problems, these children are at high risk for middle ear pathology and possible fluctuating hearing loss. Hearing needs to be tested early and frequently and treated appropriately with medications or middle ear tubes to insure the best hearing possible. Since hearing is essential to receiving spoken language, a hearing test should be done prior to an assessment of receptive language for all children with VCFS.

A child's comprehension of language is often affected differently in children with VCFS. For example, children with VCFS who also have significant developmental and possibly cognitive delays may have limited receptive language skills; they may only comprehend single words and follow simple verbal directions. In contrast, their normal counterparts at age 3 understand a wide variety of vocabulary words, multiple directions and verbal sequences as well as conversation. Other children with VCFS may function close to normal in the receptive language area. Most children with VCFS do have difficulty with abstract language to varying degrees. There are also children with VCFS who may not understand what is said because they do not process language well due to attention problems and/or problems with auditory memory. These differences in children must be taken into account when evaluating and treating receptive language problems.

Expressive Language: Gerdes et. Al. (1999) reported a wide variety of speech and language abilities in children with VCFS ranging from normal to severely delayed. They also reported that more than half of the children they saw were non-oral communicators at 2 years of age. Thus children at the age of three may be non-oral (no sounds), non-verbal (no words) or may be starting to use some single words. Other children with better language and speech abilities may, at the age of 3, be communicating in complete sentences many of which are not intelligible due to articulation errors caused by velopharyngeal inadequacy (VPI). In rare instances children at 3 may have no VPI and have fairly good speech. As speech skills improve with therapy or surgery, sentence structures also tend to improve between the ages of four and five. It is most important that a complete receptive and expressive evaluation (see previous newsletter) be done at an early age.

Speech sound development: Goldberg et al in 1993 reported that clefting disorders i.e. clefts of the secondary palate, submucous cleft palate (with clear signs such as a bifid uvula and palpable notch at the end of the hard palate), and occult submucous cleft palate (no clear signs of the palatal cleft which is "hiding") occurred 98-100% of the time in the VCF population. Two other studies (Haapanen and Somer 1993 and Weik et al 1993) have indicated that only 56% to 61% of the patients with VCF presented with structural clefting disorders. McDonald-McGinn et al (1997) and Nayak and Se, (1998) reported that 30 % to 84% of children with velocardiofacial syndrome have velopharyngeal inadequacy. However, these studies did not report on the presence of an occult submucous cleft. If the VPI is not caused by structural clefting, it can be a result of an insufficiently mobile palate, or a combination of factors such as reduced mobility, hypoplastic (small or absent) adenoids or an abnormal cranial base. In children with VCFS the skull base can be rotated away from the basicranium (base of the skull) thereby enlarging the pharynx and contributing to or causing the VPI. Those children with VPI are then at risk for developing compensatory articulations that will be discussed later in greater detail. D'Antonio et al. (2001) have reported that 90 % of the children they studied had VP inadequacy. They also reported that younger children with VCFS (under 6 years, 11 months) used fewer consonants than older children with VCFS or younger children with VPI without VCFS. They also indicated that these younger children with VCFS also used more glottal stops than either of the other two populations of children.

Resonance: Although hypernasality is another primary indicator of VPI and also a clinical feature of VCFS, the severity of the hypernasality can vary from minimal to severe depending on a variety of factors. (Haapanen and Somer 1993, Lipson et al 1991, Weik et al 1993). Because VPI has a pro-

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Defining and Addressing Speech and Language Problems . . .

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found effect on the ability of the child with VCFS to develop appropriate speech and resonance skills, a complete assessment of the palatal pharyngeal mechanism is always appropriate and this should occur as early as possible. More will be discussed about hypernasality and nasal emission in the intervention section.

To summarize, speech sound development is highly variable in children with VCFS depending on the child's degree of expressive language impairment, their auditory (hearing and listening) abilities, their phonological and articulation (sound making) skills as well as the degree of velopharyngeal inadequacy.

What should be expected if a child does not have VPI? If such is the case, he/she should be able to build oral pressure for consonant production. As a result he/she may have good sound productions without compensatory errors. The child's ability to develop verbal communication may then be limited only by the level at which his/her expressive language is functional or to the degree that other speech problems exist. If however, a velopharyngeal closure problem is a component contributing to the speech disorder, the child will have difficulty producing those consonants that require the ability to build oral breath pressure. These consonants include /p b t d k g f v s z sh ch and j/. Because the child cannot build pressure and valve the air stream appropriately at the palate level, he/she may inappropriately valve in the back of the mouth, the throat or at the vocal fold level. When this happens, sound productions called compensatory errors are produced (i.e. pharyngeal fricatives and glottal stops). Children with VCFS can have other speech problems in addition to or other than VPI. These other speech problems that interfere with articulation are dyspraxia, dysarthria or phonological/articulatory disorders. Typically children with only VPI and no other speech problems can produce low pressure sounds such as /m/, /n/, /w/ and /h/ and may even be able to use these sounds in words and sentences. When these sounds are not evident in a child's repertoire, one should suspect other problems in addition to the velopharyngeal inadequacy. It is of interest that D'Antonio and colleagues (2001) have reported that children with VCFS may have a "syndrome specific" speech profile that is different from other children with VPI.

INTERVENTION

Receptive language: The speech/language pathologist, after a thorough receptive language assessment, will select comprehension treatment goals that are appropriate to the child's age and abilities. The therapy should focus on teaching the desired words, concepts, directions, size or spatial relationships or sentence forms. Therapy requires a variety of experiences and inputs such as visual, auditory, or tactile (touch) to teach

the targeted words or word combinations. As concepts develop, ongoing therapy will address a variety of vocabulary words, relationships between words, morphological (grammar) markers and sentence structures.

Expressive Language: Intervention for expressive language therapy is incorporated into both receptive work and into the sound development therapy in which the child participates. Expressive language therapy can focus on vocabulary use, the development of word combinations, sentence structure and early conversational narrative and interactive skills. Expressive language therapy is always incorporated into any speech therapy done with the child with VPI.

Speech sound development: For the child who is nonverbal or nonvocal, speech therapy includes the types of interventions discussed in the previous article by Marrinan. Therapy will focus on the development of a speech sound repertoire, including nonpressure consonants such as /m/, /n/ and /h/ and visible pressure consonants such as p and b, (produced forward in the oral cavity). Often it is necessary to use "the nostrils occluded" technique for /p/ and /b/ to help the child to build pressure. Other techniques such as those discussed by Golding-Kushner (2001) in her published text are also effective. Suggestions for working with a child include eliciting the sound by asking the child to "look and listen" while holding the nose if the sound is a pressure sound and velopharyngeal inadequacy is present. Use imitation, touch when necessary and visual feedback. Praise all efforts when the sound is oral and not a compensatory error sound. When the sound is produced (and is not a glottal stop), the sound can be imitated in a simple (one-syllable) consonant-vowel word e.g. "pie". Children at this level of speech development are not candidates for surgical management of the VPI.

At the next level, there are children who are verbal but are only using nonpressure sounds such as /m/, /n/ and /h/, and/or glottal stops and pharyngeal fricatives. The goal for these children prior to surgical intervention is to eliminate the glottal stops and pharyngeal fricatives through the use of techniques (Golding-Kushner 2001) to prepare the child for a good surgical result. At some centers, if the child is age three to four and not ready for surgery, a prosthetic appliance is fit by the prosthodontist. This is used temporarily to assist the child with velopharyngeal closure to learn to produce sounds normally without compensatory error patterns.

The prognosis for the three to six year old child with VCFS to become verbal (e.g., use words and sentences and have an ability to produce some pressure sounds such as /p b t d/ in words) is good with appropriate therapy. Parent participation in the therapy is also crucial. Materials and books are available to assist both the speech pathologist and the parents. (Golding-Kushner 2001 and De Feo 1995). Depending on the severity of the velopharyngeal inadequacy, the child may need to occlude his own nostrils to produce these sounds. Even if consonants can be produced, the hypernasal resonance and nasal air emission continue to be obvious if the child has

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VPI. The hypernasality and the nasal airflow exist because of the VPI and are therefore not remediated with therapy.

Resonance (Surgical Intervention)

Most centers do not intervene surgically with children with VCF until the child is four or older and have some speech skills. Assuming the child is age four or five, has had effective therapy and has developed the best speech possible by eliminating compensatory errors, he/she may then be a candidate for surgical management for the VPI. The examinations required prior to surgical intervention include a Cleft Palate or VPI Team assessment by a speech/language pathologist, audiologist, and surgeon. The prosthodontist, orthodontist, dentist, and geneticist may also see the child depending on the type of team evaluation needed and the team members that are available. The evaluation will also include videofluoroscopy to evaluate the palatal pharyngeal closure in the lateral, frontal and base views. Typically children with VCF (through some pre-evaluation practice or use of rewards or encouragement) are able to complete this study because it only requires the child to be seated in a chair in the x-ray unit and talk to the clinician into a microphone.

Nasopharyngoscopy is a procedure done to directly view the soft palate (back of the roof of the mouth) and pharynx (back of the throat) as the child speaks. With this study, the clinician who does the procedure is able to determine directly whether the palate and pharynx are adequate in size and function to separate the nasal cavity (nose) and oral cavity (mouth) during speech to prevent hypernasality and the nasal emission of air. Because this procedure is invasive (i.e. it involves the passing of a very small spaghetti-like tube into the nose after the nose has been anesthetized) the child might be anxious and may initially struggle. However, with caring, some physical control, urging and rewards, most children do eventually allow the passing of the scope into the nose (Shprintzen, 1997). Once the scope is passed and the child recognizes that there is no pain, he/she often performs appropriately by repeating the selected words and phrases after the speech/language pathologist. The combined results from the videophonation study and the nasopharyngoscopy provide the Cleft Lip and Palate Team or the VCF Team with the appropriate information to determine the best surgical decision. Because children with VCF frequently have abnormal blood vessels in the pharynx, magnetic resonance angiography (MRA) is also completed prior to surgical planning to determine the presence of abnormal vessels and their pathways.

When a team of professionals discuss the pros and cons and the possible options, the best surgical decisions are made. In this clinician's experience, palatal lengthening procedures such as the Furlow have not been helpful in this population when there is motor involvement of the palate and the low muscle tone associated with VCF. Some surgeons use pharyngoplasty such as the Orticochea procedure in children with VCF but the speech results are not available. It would seem that if the low muscle tone and an abnormally large nasopharynx were issues,

the use of this procedure would be in question. Based on this clinician's experience, the greatest speech and resonance success has been achieved by those surgeons who use the high, wide pharyngeal flap described by Argamaso (1995).

In summary the following recommendations should benefit children with Velocardiofacial Syndrome in the 3-year to 6-year age group and beyond:

- A full team evaluation should be done of the child's speech readiness for surgery and of the velopharyngeal closure issues. An evaluation of the child's language/learning and behavioral profile should also be obtained. The team should consist of professionals who are knowledgeable about VCFS and VPI.
- Instrumental studies such as videofluoroscopy and nasopharyngoscopy need to be completed.
- Surgical decisions for children with VCFS are typically not made until the child is four or older and not made until the child has some speech which can be replicated. He/she needs to be able to imitate sounds. The majority of glottal stops and pharyngeal productions should be reduced or eliminated.
- A discussion should be held with the surgeon regarding the number of procedures done for children with VCFS and the speech outcomes. Nasal and oral breathing outcomes should also be questioned particularly with regard to being able to breathe comfortably during sleep, while eating and during exercise post surgically.
- An MRA should be done to determine the presence and course of abnormal blood vessels in order to ensure the safety of the surgical procedure.
- A post surgical speech reassessment by an experienced (with VPI) speech/language pathologist should be done. Specific recommendations should be shared with the family and the attending speech/language pathologist.
- Speech therapy should be continued to address the child's specific speech and language needs. Phonological and other articulation errors that are not related to the VPI may need to be addressed. In addition the child will continue to need intervention to improve his/her comprehension of abstract language and to further develop and expand expressive language skills. As the child approaches the age of six, the speech/language pathologist will want to focus on social language and pragmatics, i.e. use of language in context.
- Of most importance is that parents are a critical member of the diagnostic team and a key member of the intervention team throughout the child's preschool and school age years. Only through daily practice at home will your child achieve his highest communication potential.

(References: Continued on page 7)

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The author wishes to express her gratitude to her colleague, Susan Carneol, for her valuable suggestions in this article.

2002 Conference Accommodations

The conference will be held at the Moat House Hotel in Northampton whilst some accommodation and the Saturday night 'Fun Night' will be held at University College Northampton campus. Northampton is approximately 60 miles from London with the nearest airports being London Heathrow, London Luton and Birmingham International. For those intending to visit a little of the country before or after the meeting, it is recommended that you hire a car to get you from the airport to Northampton. Accommodation is also available at various other hotels around and outside the city. Please contact all hotels directly saying that you are attending the UCN Conference in July 2002.

The Moat House Hotel, Silver Street, Northampton NN1 2TA has offered delegates a special rate of £30.00 bed and breakfast per person per day based on 2 people sharing a room. Tel: +44 (0)1604 739988, www.moathousehotels.com

The Hilton Hotel, 100 Watering Lane, Collingtree, Northampton NN4 0XW is holding 20 twin (ideal for families) and 10 double rooms for the Friday and Saturday nights and 10 twin rooms for the Thursday night before the conference at a rate of £30.00 per person per night for bed and full English breakfast. Dinner, bed and breakfast would be £45.00 per person per night. If children share a room with parents they are included in their rate. Children 15 years old or over will have to pay for breakfast. This special rate will be available until the rooms are taken or until Friday, 31st May 2002. If you want to reserve a room you can do this by quoting **UCN 250702** either by telephone, fax or email. Tel: +44 (0)1604 700666, Fax: +44 (0)1604 702850, Email: reservations_Northampton@hilton.com, web site: www.hilton.com (**PLEASE NOTE THAT RESERVATIONS AT THE SPECIAL RATE CANNOT BE MADE THROUGH THE WEBSITE**)

The Poplars Hotel, Moulton, Northampton NN3 1RZ is a small country hotel of character, situated in the village of Moulton only 4 miles from the centre of Northampton. They offer traditional home-cooked food both at breakfast and dinner. All rooms have colour TV, tea and coffee making facilities and most rooms are fully en-suite. Rates: Single room, bed and breakfast £27.50, Single room, ensuite, bed and breakfast £48.50, Double or twin-bedded room with shower or bath (2 people) £59.50.

Tel: +44(0) 1604 643983, Fax: +44 (0) 790233

Note: As of 11/7/01, the approximate conversion rate is — 1.3 U.S. dollars to 1 £ (British pound) so £50 is approximately \$65.00 (US).

c/o Upstate Medical University Hospital
Communication Disorder Unit, Rm 708
750 E. Adams Street
Syracuse, NY 13210

Phone: 315-464-6590
Fax: 315-464-6593
Email: kelvin@vcfsef.org

Your VCFS information source

We're on the web:
www.vcfsef.org

2001 BUSINESS Meeting Minutes

1. Budget & Treasury report: The Foundation was granted 501(c) 3 tax exempt status this year and the Secretary_Treasurer has established a new account for the Foundation. The Foundation continues to meet its expenses and will finish this year's meeting with a small balance in the account, consistent with previous years.

2. Nominations and Elections:

President: Julie Squair (Milton Keynes, England); Secretary-Treasurer: Lisa Jennings (Weymouth, MA); Member Council: Linda Oppen (Boca Raton, FL) as Lay Council Member; Stephan Eliez (Geneva, Switzerland) as Professional Member.

Committees to be formed:

Nominating Committee – 2 lay/2 professional: Ahmad Al-Khattat (Northampton, England) elected chair.

Liaison Committee – Maureen Anderson (Salem, NH) elected Chair.

Committee on Committees – Fred Berg (Sterling Heights, MI) elected Chair.

3. Atlanta meeting

Concerns raised regarding understanding of Foundations mission and role have been satisfied. Sponsors of Atlanta conference: Children's Hospital of Atlanta (CHOA), VCFSEF, Center for Disease Control (CDC) and Emory University. The next Executive Director of the Foundation (to be named in 2003) will be work with Atlanta group and report back to Board. The Board is committed to Atlanta.

4. Location for 2003 meeting: Possibly San Diego, CA. Alternately, Syracuse, NY

5. Plans for England – July 26-28, 2002 – Northampton, UK.

University has assigned an administrator. A variety of accommodations have been discussed, from dormitory rooms to hotel and Bed & Breakfast. Relative to tax status, in UK their local support group is a registered charity. Need general estimates as to number of member will travel to UK. Solicit (hand) count at Business Meeting (today) and in the next newsletter. Revisit last year's proposal: set aside some funds for financial support from US to UK travel.

What's New At the Foundation!

Good day, ladies and gentlemen! As you can see, we are once again trying to upgrade the look of The Foundation Newsletter — make it easier to read and retain. Pretty soon, I'm going to get it right (smile) and, hopefully, in doing so, be able to get them out to your more quickly.

We have recently upgraded our web site provider, though there are few visible signs of that yet. The biggest one, right now, is that when someone makes an initial inquiry to the email "info@vcfsef.org", they get an autoreponse message highlighting the information on our web site. I also plan to implement a number of things including a few quick response forms for things like signing on for our newsletter & email lists, conference preregistrations, FAQ input, feedback forms and the like. No definite implementation dates yet, but we'll keep you informed. As usual, if you have a suggestion, email it to me at kelvin@vcfsef.org (until I get the form build and implemented) and I'll be happy to review it.

I hope everyone enjoys their holiday season and remains happy and healthy throughout. In the meantime, have an AWESOME kinda day.

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

6. Interactive Website

Discussion related to setting up a new part of the Foundation website whereby questions could be asked and responded to via Foundation. Need to work on FAQs, and structure to review questions and solicit professional responses. To be discussed at interim Board meeting.

Meeting adjourned.

Initial Committee Reports:

Liaison Committee: Maureen Anderson (NH), Chair. Members: Beth Miller (ME), Susan Knapp (FL), Valerie Bonds (AL), Wendy Kates (MD) & Lisa Jennings (MA)

Mission: to connect with various organizations to apprise them of the existence and purpose of the VCFS Educational Foundation.

Nominating Committee: Ahmad Al-Khattat (UK), Chair. Members: Liz Romanelli, Susan Wirth & Robert Squair.

Mission: to determine professional & lay members to be considered by Board & membership for election to Board or committees. Discussions will continue to determine nominees for 2002 Board (1 lay & 1 professional member) and recommendation for the Editor to continue for another term.

Committee on Committees: Fred Berg (VA), Chair. Members: Joe & Sheryl Abruzzi, John Robbins, Donna Landsman, Marc Weinberg, Jerry & Judi Gaughran.

Mission: to discuss and formulate topics that may be developed by establishing a formal committee in the forthcoming year. Focus on the immediate needs and direction of the Foundation and its membership.

Recommendations:

1. A committee to be established for fund raising to take the Foundation to the next level for regional/national exposure for educational purposes.
2. A committee to be established to identify what topics the majority of the membership would like presented at future meetings.
3. A public relations committee to be established to promote the video presentation that is currently under development.
4. A committee developed to form a liaison with the National Alliance For The Mentally Ill in Washington, DC