

VCFSEF NEWS

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Executive Director's Report

Executive Director's Report

Karen Golding-Kushner,
Ph.D.

I am pleased to report that our tenth annual international scientific conference, which was held July 23-25, 2004 in Atlanta, Georgia, was a rousing success. Over 350 attendees heard presentations by 93 speakers from over 15 countries. Topics were epidemiology, clinical and molecular genetics, speech, language and feeding, immunology, dentistry, cardiology, psychology, psychiatry, neuroimaging, coping and advocacy, and others. There were 73 visits to the speech, feeding, leg pain, and education clinics conducted by internationally recognized experts in treating VCFS/22q11.2 deletion syndrome.

This year we introduced breakout specialty sessions during breakfast and lunch. There were as many as 210 participants during each. These programs enabled small groups of attendees to participate in discussions with faculty members on a variety of topics such as cardiology, speech, diagnostic labels, and support groups.

Feedback about these sessions was very positive and we plan to continue them at future conferences. If you have ideas for topics and facilitators, please let us know!

While the adults learned and socialized, the children had a blast at Kid's Camp, which was attended by 65 children and staffed by 35 volunteers. Monica Townsend-Mervin, who just completed her term as President of the Foundation, Karlene Coleman, and their committee did an amazing job organizing the activities, entertainment, and supervision.

Special thanks to Gail Klein and the Department of Continuing Education of CHOA, which raised funds and received grants that allowed us to bring in more speakers than usual and also enabled us to introduce the breakout sessions during breakfast and lunch. The entire program committee worked tirelessly organizing the meeting: Maureen Anderson and Bob Shprintzen for the VCFSEF, and Bill Mahle (my co-chairperson), Karlene Coleman, and David Ledbetter for the 22q11.2

Deletion Group, with whom we held this joint meeting. You can see some photo highlights of the meeting elsewhere in this newsletter.

In keeping with our Mission to disseminate educational information about VCFS, we are making as many presentations available at no cost as we can. All but five speakers permitted audio recording of their sessions. Tape cassettes or a CD of the meeting can be ordered from Conference Copy. An order form is included in this newsletter. Almost all of the speakers also gave us permission to upload copies of their talks to our website, and thanks to the hard work of Kelvin Ringold, webmaster, and volunteers Frank Shoemaker and Marta Perez-Stable, those 85 presentations should be available by the time you read this. Speaking of our website, our web team has given the site a completely new look and design. Please be sure to visit and let us know what you think! We appreciate your suggestions. We were able to make these changes thanks to our volunteers.

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SAVE THE DATES!

... for the International Scientific Conferences

- **2005:**
July 28-30, 2005
Syracuse, NY
- **2006:**
July 7-9, 2006
Strasbourg, France
- **2006:**
November 2-4, 2006
Brisbane, Australia

Executive Director's Report *Cont...*

(Continued from page 1)

While the 2004 scientific meeting was occurring, planning committees met to discuss future conferences. Our next conference will be in Syracuse, New York, July 28-30, 2005, at the Sheraton Syracuse University Hotel & Conference Center. Dr. Robert Shprintzen, local arrangements chair, negotiated an excellent room rate and we will publish details and the Call for Papers very soon. Please be sure to sign up for email updates! We will also send out a regular mailing, so if you are not on our regular mailing list, send me your full name and address. We do most of our communication by email, so let me know if you do not have access to the Internet and must receive notices we send by email in the regular mail. We are interested in your program suggestions, so please contact me or Dr. Shprintzen with your ideas as soon as possible. Both of our email addresses appear on the Board list below.

The dates are also set for the two conferences we will have in 2006. The first will be held July 7-9, 2006 in Strasbourg, France. Dominique and Jean-Louis Pfeiffer are handling local arrangements for that meeting. Dominique is Chair of Generation 22 (www.generation22.asso.fr), the French VCFSEF association, which will host our meeting. She can be reached at dpfeifer@generation22.asso.fr. Dr. Stephan Eliez, VCFSEF Regional Director for Europe, has worked diligently to bring

national scientific and support groups from many European countries together in a federation under the Educational Foundation umbrella to improve communication and dissemination of information to the professional and lay communities. We look forward to the participation of all of the groups in conference.

Four months later, from November 2-4, 2006, we will head down under for our meeting in Brisbane, Australia. Stephen Russell is handling local arrangements there. His name should be familiar to you because he is the VCFSEF Regional Director for Australia and the Pacific Rim and also Director of VCFS Queensland, Inc. I had the pleasure of visiting Brisbane at the invitation of VCFS (Qld), Inc. a few years ago and the hospitality afforded me was incredible. We eagerly anticipate participation in this meeting by attendees from around the globe.

See you all in Syracuse!

Karen Golding-Kushner, Ph.D.
Executive Director



Alexandra Oppenheimer, BA, M.Ed. addresses banquet attendees in Atlanta.

Call for Newsletter Submissions

The VCFS Educational Foundation wishes to reflect the views and experiences of a wide variety of its lay and professional members. Please contact the Editor, Eileen Marrinan at 315-464-6580 or via email to marrinae@upstate.edu with your ideas or submissions.

The last newsletter is now available in Arabic, Hebrew and Spanish.

New Support Groups are forming.....

Dallas -

Contact: Keri Alexander
411 Fall Creek Drive
Richardson, TX 75080
972-889-1103

A family fun event is slated for Saturday, February 19, 2005 1-3pm.

New Jersey -

Contact: Yolanda Ortiz at
PaulW28165@aol.com

Sharing Amanda's favorite hugs

By Mary McPherson

Amanda McPherson was a precious, sweet pixie of a girl who touched the lives of so many people. Although Amanda struggled with many problems in her short life, she always tried her best and shared her love and wonderful hugs with everyone she met. After Amanda's sudden death in December 2003, Amanda's family and friends started the Amanda McPherson Foun-

dation to keep Amanda's sweet, loving spirit alive by doing good things in Amanda's name. One of these "good things" is to support the Velo-Cardio-Facial Syndrome Educational Foundation (VCFSEF). The support that our family received from VCFSEF made an incredible difference in Amanda's life and our family's life. Through monetary donations, the foundation hopes to help other families receive early diagno-

sis, appropriate treatment plans and much needed emotional support just as our family did.

Amanda was born on June 17, 1995 and within days doctors discovered she had Tetralogy of Fallot. While waiting for her heart surgery, Amanda struggled for several months with eating and nasal regurgitation. She was hospitalized several times, but no one was able to put the pieces together for a

Update from Australia

Stephen Russell

There have been a number of very positive developments here in Australia.

First, six members of our Management Committee attended the recent meeting in Atlanta, Georgia, co-sponsored by the VCFS Educational Foundation Inc. and the 22 q11 Deletion Group.

Our Committee (Steve and Kathy Russell, John and Judi Giles and Greg and Melissa Uptin), staffed a table in Atlanta and distributed information packs promoting the **meeting in Brisbane, Australia from 2 to 4 November, 2006**.

This meeting is a joint meeting of the Foundation and the VCFS Foundation of Queensland (Australia).

Soon after the Committee's return, we staged our annual black tie fundraiser - the Faces of Sunshine Ball - which was both well attended and patronised. We

raised approximately \$70,000.00.

The following weekend, our Foundation held a family day (in tandem with our AGM). Not only did all kids and parents have a wonderful time (including petting the baby farm animals who visited!), but our Management Committee welcomed three new members.

And, finally, on 1 October, 2004 the management committee met with senior executives of Mater Health Services of the Mater Hospital here in Brisbane. This was the first planning meeting for the establishment of Australia's first ever multi-disciplinary VCSF clinic. Despite a target date of 2006, we are in fact hoping to open the clinic before the end of this year.

The Queensland Foundation extends its heartfelt thanks and congratulations to the executive of the VCFS Educational

Foundation Inc. for staging a wonderful meeting in Atlanta and we all look forward to seeing you in Syracuse next year.

Steve Russell,
President



Steve Russell (right) promotes 2006 conference to be held in Brisbane Australia.

Sharing Amanda's HUGS cont...



diagnosis. We struggled to understand what was wrong with our little girl. After reading the book, *The Heart of a Child*, we sought the advice of a geneticist who quickly determined that Amanda had VCFS. The only information available at that time was one singled-sided sheet of paper.

Thankfully, we found the VCFSEF and finally, we had some answers. As most of you can appreciate, just knowing that you are not alone and that there is someone and somewhere to go to for help is an incredible relief. Our family attended the conference in Stanford and took Amanda to meet Dr. Shprintzen to discuss an appropriate treatment plan for her. Thanks to the wealth of information available from VCFSEF, Amanda received all the necessary therapies to be successful. We were convinced that the early intervention and continuing support that she was receiving from the school district would make her a VCFS success story. After such a scary start, she was growing up to be

a beautiful, fun-loving little girl. Just like her friends, she loved Barbie and Sponge Bob, she played soccer and softball, and she loved to giggle with the girls and chase the boys at school. Unfortunately, we will not be able to see how successful our Amanda would become. Amanda contracted a virus that attacked her heart causing it to stop, a condition known as Viral Myocarditis. Our little fighter could not fight this one off. Since Amanda's death, we have learned that you can either chose to be bitter or chose to be inspired. Our family is choosing to move forward, to be inspired, with the help of our friends and community and all the people who were touched by Amanda. We feel that supporting the organization that helped us through such a difficult and confusing time is a good thing that we can do in Amanda's name. Amanda was famous for her hugs, where she would practically wrap her whole body around you. Donating to VCFSEF is our family's way of sharing those hugs with others! §

The VCFS Educational Foundation has established the Amanda McPherson Fund. Donations to that fund will be used to help meet our educational goals.

tanner addresses annual conference

Raymond Tanner

Congratulations to Raymond Tanner, a lay member of the VCFSEF from Australia who was elected to our Board of Directors in July 2004.

He wrote a speech that was delivered to the Parliament of South Australia in 2003, and has recently published a book entitled "Footprints of Hope: VCFS (Velo-Cardio-Facial Syndrome). Mr. Tanner delivered the following speech at the 10th annual VCFS Educational Foundation and the 4th International Conference for 22q11.2 deletions held in Atlanta, GA, July 2004.

Dr. Golding-Kushner, faculty members, delegates and guests, this is indeed a privilege and honour to be able to talk to you this evening about my book VCFS— Footprints of Hope and also about the success of obtaining recognition from our South Australian State government and opposition on promoting awareness of VCFS. I would also like to thank Dr. Golding-Kushner and the planning committee for inviting me here.

My life with VCFS changed dramatically three years ago, when my wife and I, learned that our first son James, who died at the Adelaide Children's Hospital 18 years ago this October – aged 9 days old, had his heart and brain removed for research without our permission. This practice became known as the "tissue retention crisis", and my wife, Ruth, and I found out about this by accident while listening to a local talk back program on the radio. Many families were so shocked about this terrible practice and in particular finding out that their love ones had been violated that they have decided to sue the hospital. Although Ruth and I thought about doing the same, after a few days, and some debate, and eventually speaking with the lawyer who was handling this case, that we decided not to follow other families' quest to gain financial benefits from this awful practice as we

believed that this would not gain any real benefits, only more sorrow. As a result, we both decided that James heart should stay at the hospital for research, as his heart had already helped many cardiologists and cardiologists in training and we were also advised by the hospital's pathologist who



The Author: Raymond Tanner

topsy on James that even one of the top specialist from the UK Professor Bob Anderson, from the Hospital for Sick Children, London, who visited the Adelaide Children's Hospital in 2001, was able to learn things from James' heart that he had not seen before. We advised the Minister for Health, South Australian government, in writing giving our approval for James' heart to stay at the hospital for research as we also felt that the research may help other children with heart defects – in particular children with VCFS.

You may be wondering what this has to do with the book. As stated, this information was to change my way of thinking about VCFS and where I stood in society. When I was diagnosed with VCFS 11 years ago, I was in a void, not too sure, which way to go. Many of you who have been diagnosed with VCFS as an adult will know what I mean. I also wondered why I had to suffer this syndrome for years without having a name to it. Knowing that James' heart was being kept, made me realise that James and I were put here for a pur-

pose and that his death should not be a waste. As a result I felt that I needed to tell my story and my son's story. My second son Andrew, who is 16, also has VCFS.

Hence the book was born. The title of the book is a result of our first son's footprints being taking by the nurses at the Adelaide Children's Hospital 7 days before he died and which coincidentally was on my birthday, 23 October 1986. These footprints are very special to my wife and me. The title word hope is to give families, indirectly or directly affected by VCFS, some hope for the future - they are not alone. Initially the book was going to be about my life struggles – school, work and society in general; our first son's short life; and our second son's struggles in growing up; my wife's traumas; additional information etc. However when the first draft was done, the book felt empty. When I was doing some research for the book on the web, I found some support groups – and many of you who are at the conference are from those groups, and I realised that there is a world out there with other families who have had different trials and tribulations regarding a VCFS child or as an adult. After putting some postings on the sites I received various replies back from parents and the book grew from that.

The book from its original platform has changed a lot, and credit for this must go to Dr. Shprintzen for his time and help during the early stages of the book, and also for his time in writing the foreword. Also a great thank you also goes to Suzi Drevensek for her support in writing the chapter on VCFS and she is also here at the conference. Thanks must also go to the VCFS foundation QLD Inc for their support. Some of their members and president and his wife are here. I thank, of course my son Andrew and daughter Claire, and my wife, who unfortunately could not make it to the conference. She is home

(Continued on page 5)

Address to conference cont...

(Continued from page 4)

looking after the bills, the garden, making quilts for the VCFS foundation QLD ball in September (it will happen this year Steve and Kathy), taking Andrew to Women's and Children's Hospital Cranio-Facial clinics etc, house work, and so on. She is a very special person to me and without her I would not be here tonight.

Since knowing about James and my involvement with the VCFS Foundation, South Australia Inc, I have been writing to the Minister for Health the Hon. Lea Stevens, mp South

Australian government and also to the Shadow Minister for Health and deputy opposition leader the Hon. Dean Brown, mp. Both the Minister and Shadow Minister have given me great support and in September 2003, the Hon. Dean Brown asked me to write a speech on VCFS for him so that he could present it in the South Australian parliament. This speech was given on the 23 September 2003, and I have a copy here if anyone wishes to read it or one can go onto the south Australian parliament web site and look up Hansard recordings. In addition, I also wrote an email to the Minister for Health in December 2003 to see whether I could get a grant for the book - and like many medical professionals know - getting a grant from the government is not easy. However to my surprise, I received a letter from the minister on 7th January 2004 my second son's birthday and three weeks after my initial request, that the minister agreed to give a donation to the VCFS Foundation SA Inc so that the book could be published, so as to promote awareness of VCFS. The only condition was that she received a copy of the book - which of course she now has. In addi-

"three years ago... I, learned that our first son James, who died ... aged 9 days old, had his heart and brain removed for research without our permission. "

tion to the South Australian government support, we are also waiting feedback from the Australian federal government to see whether VCFS children under the age of 16, will automatically be entitled to government financial assistance instead of going through the normal red tape. I wrote a submission late last year and the government agency responsible is still reviewing the submissions.

Foundation Inc for the Dr. Tony Lipson memorial fund and other projects the board feels appropriate.

For those of you who do not know anything about Dr. Lipson, he helped create the first VCFS support group in Australia 12 years ago, which is based in Sydney NSW. Dr. Lipson died in a car crash a few years back.

Thank you for listening and I hope you get some benefit from reading the book, and there is definitely hope in the future with having VCFS.

Editors Note: Information on Mr. Tanner's book is available on the VCFSEF web site.

The VCFS Educational Foundation relies on dues and contributions to fulfill its mission to disseminate educational information about the syndrome. We gratefully acknowledge the following individuals for their donations, which were made since our last newsletter.

In memory of Jacqueline Kristo:

Paul and Jill Atkinson
Don and Claire Fox
Joe and Dee Fullmer
Lori Tierney

In memory of Melissa Ger

Beber and Associates

In memory of Amanda McPherson

The Amanda McPherson Foundation

Caitlin Lynch Memorial Fund

Debra Gollehon
Susan and Greg Knapp
Deborah J. Menter
Connie Mueller
Linda C. Opper

Tony Lipson Memorial Fund

Debra Gollehon
Susan and Greg Knapp
Deborah J. Menter
Connie Mueller
Linda C. Opper

In honor of Bob Shprintzen

Joe Abruzzi

In memory of Mitchel Kalata

Franklin Square Senior Center

In memory of Ira Shprintzen (Bob Shprintzen's brother)

Karen Golding-Kushner
Wendy Kates
Eileen Marrinan

General Fund

Michael Cabral
Michael Joseph Cabral
Fredrika Millett Camozzi
Cathy and Alexander Cheng
Gale Norman Coston
Ronda and Michael Golden
Jeff and Donna Landsman
Deborah J. Menter
Howard and Sandra Olson-Miller
Suzi Oppenheimer
John E. Riski

Your regional directors



Ahmad Al-Khattat
United Kingdom

Ahmad Al-Khattat is a Podiatrist working in the UK. He has been studying the phenomenon of leg pain in VCFS since 1995. He has attended all the Foundation's meetings since 1996 and took part in organising the 2002 meeting in Northampton UK. He was elected a member of the Board of directors of the VFFS Educational Foundation in 1998 for a 3 years term. He was subsequently elected as a chairman for its nominating committee." Last year he was elected VCFSEF CoRegional Director for the United Kingdom (with Julie Squair).

There are a number of active VCFS support groups and research centers in the UK and in Europe. Together with the European Foundation's office headed by Dr Stephan Eliez, the UK office is hoping to take part in bringing these different activities together to in an attempt to amalgamate the efforts of such various organisations that are working for the same aims and objectives. The VCFS Educational Foundation remains the central processing unit for all these efforts, which will hopefully attract others to join in.



Julie Squair
United Kingdom

I was thrilled to be elected as Regional Co-Director for the UK and Ireland and look forward to helping fulfil the aims and objectives of the VCFS Educational Foundation from this side of the world. In the UK we are lucky to have several groups who are working hard to give support to families on a daily basis. I hope to be in regular contact with all these groups in the not too distant future in order to form a link between them and the Educational Foundation.

On a personal note, I am the parent of a VCFS child and one of the founding members of The 22q11 Group in the UK. I was privileged enough to be able to attend the first VCFSEF conference in New York in 1995 when Hazel was almost five years old, and find it hard to believe that she is almost 16 years old and leaving compulsory education in summer 2005 how time flies!

Originally qualified as a bilingual secretary (almost 25 years ago now!), I now teach Spanish to adults. I also spent the last school term teaching 14/15 year olds – many of them with learning difficulties. That was an experience!



Stephan Eliez, MD
Europe

I am a child psychiatrist, with training in medical genetics. Early in my professional training, I developed a strong interest in VCFS. I thought a better understanding of how children and adolescents with VCFS develop would help us take care of potential problems earlier and treat individuals more efficiently.

In 1997, I went to Stanford University in California for 4 years. There, we built an extensive research program combining genetics, neuro-imaging and cognitive neurosciences in VCFS.

During the same period, I worked with the local Northern California VCFS Support Group to increase knowledge and awareness on VCFS in the community, and became an active member of the VCFS Educational Foundation.

In October of 2001, I relocated to Switzerland (my native country) and started a research and a clinical program on VCFS in Geneva. I am a board member of the Swiss and French VCFS support groups (Connect22.ch and Génération 22). I strongly believe that there is a considerable benefit for national and international VCFS family associations or foundations to unite and work together. Together, we will get more attention and resources to improve the life of individuals with VCFS and their families.

Your regional directors



Doron Gothelf, MD
Middle East

I am an adult, child and adolescent psychiatrist working at Schneider Children's Medical Center of Israel. I have been studying VCFS for almost a decade, with a focus on its emotional, behavioral and psychiatric characteristics and their treatment. I have always believed that children with developmental disabilities should be treated in a single clinic situated within a children's hospital so that it could provide for all their medical and psychosocial needs and also support family members.

For these reasons, about 3 years ago, I established the Behavioral Neurogenetics Clinic for the treatment and study of subjects with VCFS and Williams syndrome. The clinic is so organized that all medical treatment is offered to individual child in one concentrated day. It also works closely with the parents' association and offers a wide range of psychosocial programs and activities, such as parental support groups, big brother programs, and social and sexual education groups. We aim to serve as a "second home" to children with VCFS and their families.

The clinic is currently attended by about 120 patients with VCFS from all over the country, both Jews and Arabs. As such, we believe the clinic can also serve a wider role, as part of a bridge to peace. This is especially important in these days of growing tension in the Middle East. As a first step, we translated the Foundation's last newsletter into Arabic and Hebrew, for distribution to our neighbors.

This year, I am currently on sabbatical at Stanford University, in the Department of Child Psychiatry. Please do not hesitate to contact me for any information on VCFS.



Steve Russell
Australia/Pacific Rim

Steve Russell is the Foundation's Regional Director for Australia and the Pacific Rim. Steve is President of the VCFS Foundation of Queensland, Australia, which he and wife Kathy (secretary of the Queensland Foundation) established in 1997. Steve is also chairman of the Australian national VCFS Foundation, formed last year.

Steve is married to Kathy, and has six children. He lives with his family in Brisbane. Steve is a lawyer, and has his own practice in Brisbane, specialising in Commercial Litigation and Corporate advice.

He lists his interests as reading, golf and rugby. He is a (lapsed) marathon runner.



Antonio Ysunza, MD, ScD
Latin America

Greetings from Latinoamérica to every one in the Velo-Cardio-Facial Syndrome Educational Foundation, Inc. My first contact with Velo-Cardio-Facial Syndrome was twenty years ago when I was doing a post-graduate fellowship with my professor and now good friend Bob Shprintzen in New York City. At that time I was a physician finishing a residency in Audiology, Phoniatrics and Clinical Electrophysiology. During these twenty years, in my Hospital at Mexico City, we have gone through a necessary learning curve concerning the identification of cases. At this point in time, everyone in my center is familiar with the Velo-Cardio-Facial Syndrome. However, we are still looking for better diagnosis and treatment options for our patients. It will be my pleasure to offer all the information available to anyone in Latinoamérica who is interested in Velo-Cardio-Facial Syndrome. I will be delighted to provide all the information in Spanish if necessary. I have already translated the last Foundation newsletter into Spanish.

Please, feel free to contact me anytime about information regarding VCFS.

The art of negotiating: Dealing with problems efficiently

Coby J. Anderson, J.D. & Linda L. D'Antonio, Ph.D.

Negotiating for the needs of your child can be time consuming and frustrating. Many negotiations result in overt conflict, and conflict is costly in terms of time, money, and emotion.

There are a variety of ways you can deal with conflict:

- You can avoid it to preserve the peace but this usually weakens the relationship in the end and your needs are not met
- You can compromise or accommodate, which preserves the relationship, but this can result in a lose-lose outcome when no one gets what they wanted,
- You can compete but this usually results in a win-lose, or at best a tie, you may achieve your goal but weaken the relationship
- Or, you can collaborate.

Our premise is that collaboration, working together with the parties involved is the most effective and in the end, the least costly method for dealing with conflict. It has the greatest potential for achieving your goal while building the relationship. In short, collaboration has the best chance of achieving a win-win or all gain outcome.

Fisher and Ury (1981) have described a very effective method for dealing with conflict called Principled Negotiation. This was developed at the Harvard Negotiation Project and is described in the book "Getting to Yes" which is readily available and easy to read. This method emphasizes deciding issues on their merits rather than through a haggling process focused on what each side says it will or will not do. It suggests you look for mutual gain, not win-lose or even win-win, but all gain. Principled negotiation allows you to reach a gradual consensus on a joint decision efficiently without all of the costs that can occur when people dig into positions. It is likely that you may already be using some or all of the principles described in this method. But, if you are like most of us, it is very helpful to have these principles laid out in a structured manner so that it is easier to follow and use. Principled negotiation is an "all purpose" strategy. It is useful in all areas of your life, not just in negotiating for your child's needs.

There are 4 key elements to Principled Negotiation:

- separate the people from the problem
- focus on interests, not positions
- invent options for mutual gain
- insist on using objective criteria

Separate the people from the problem

Each person in a conflict has two kinds of interests, substance (that is, the issues(s) you are in conflict over) and, the relationship. Unfortunately, the relationship tends to get entangled with the problem

and we treat the people and the problem as one. So the first step in effective conflict resolution is to separate the relationship from substantive issues. Over the course of your child's care you will have relationships with a variety of people doctors, therapists, teachers, coaches etc. The goal of principled negotiation is to deal with the substantive issues while maintaining or building these relationships.

Focus on interests not positions

The second element in effective negotiation is focus on interests not positions. This principle underlies every form of mediation. In negotiating, ask "why" you want something. Why does the other person want what they say they want? These are your interests.

Your position is something you have decided upon. Your interests are what caused you to decide. Interests are what motivate people but they may not be easy to see on the surface. In negotiating you want to focus on interests to find issues that may be shared or compatible. But it is important to remember that agreement is often made possible exactly because interests differ.

Invent options for mutual gain

Interests are why you need what you are asking for. **Options** are ways to get what you need. The best outcome occurs when the interests of both parties are met. However most often people think the only solution is win/lose or compromise and split the difference. The more options you have and the more creative you are in brainstorming options the more chances you have for getting what you need. Separate inventing options from deciding on options. Some strategies for inventing options are:

- brainstorm as many ideas or options as possible
- be creative
- do not judge any suggestion

Insist on using objective criteria

When you are negotiating for your child most of the time both sides will say they want a "fair" solution. But what is fair? How do you decide? Look for external standards and use these external standards to support your interests. This is especially useful when there is a significant difference in power between the negotiators. An outside source helps to balance power. Possible standards might be:

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The art of negotiating: Dealing with problems efficiently *Cont...*

(Continued from page 8)

- scientific data
- expert opinion and experience
- Precedents
- accepted standard of care

Using objective criteria allows you to focus not on what the other party is willing to do but how the matter **should be decided**.

Preparation

I once had a very successful boss who would often tell me, "the better prepared I am before I go to Court, the luckier I am in the Court Room." I suspect his success had very little to do with luck. The best way to ensure you have a successful negotiation is to be prepared when you walk in the door

The Authors of "Getting to Yes" have provided a workbook for preparing to negotiate. The first thing they say to think about when preparing for a successful negotiation are interests, why do I want what I want, and why doesn't this other person want to give it to me. Questions you want to ask when thinking about your interests are: What do I care about? What am I worried will happen if I don't get what I want? The answers to these questions are your interests. Write them down, and then prioritize them. What do I care about most? What am I most afraid of? This way you know which "interests you can give on, and which you must hold firmly.

The next thing is to switch seats at the table. You need to think about what the other party's interests might be. Put yourself in their shoes. Ask those same questions from their point of view. One very good way to do this is to role-play. Have another person play you and you move to the other side of the table, then think about what you would want if you were sitting in their seat.

The next question to ask in preparing for a successful negotiation is "what do I do if we can't agree." In other words, what alternatives do you have if you can't come to an agreement with this person? The authors of "Getting to Yes" refer to this as your BATNA (Best Alternative To Negotiated Agreement). Knowing your alternatives will affect the way you negotiate. For example, if you go into a job interview and have three other offers with firm salary amounts, you will act differently than if you have no other offers and are two months behind on the rent.

Lets take an example. Your want your pediatrician to give you a referral to a specialist, and he won't do it. If you can't come to an agreement with this doctor, what are your alternatives?

You can get another doctor. But what if your insurance plan only has three pediatricians, and they are all partners. You could change plans. You could see a private physician who you will have to pay for. The point is you need to know when you sit at the table what your alternatives are and how realistically attractive they are. Something that may come up when you are researching options is that you find your best alternative is better than anything you could get out of this negotiation. Lets say you call around to see what other doctors are available on your plan and find one who is world famous in handling children with VCFS and she agrees you need a referral. Your BATNA is now more attractive than your best outcome from negotiation could bring.

Like interests, you also need to think about the other person's BATNA. It may be that the pediatrician's alternative to agreeing with you is that he has one less difficult patient to deal with. On the other hand, a school district negotiating on speech services might lose money if you move to another school, so they may negotiate differently.

One quick point about BATNA, be realistic about what you will really do.

The way some people think going into a job interview is "I can go back to school, or take a year off and go to Paris, or work for my uncle at the grocery store, or move in with my parents until I find a job." Thus they think they have lots of options and enter the job interview with that mind set. But, the truth is, you only get to do one of these things. So look for your best realistic alternative that you will follow through on if this negotiation fails, then take it with you to the table and act accordingly.

Options are the ways to satisfy your interests. The important thing to remember here is that we want as many options as possible. Don't filter. Don't say, "Oh that won't work," because a really crazy idea may lead you down a path you hadn't thought of before, which may be the path to the answer. When you begin to think about options write them down. Remember to separate the creative process, finding options, from the decisional process, choosing options. Just because you think of an option doesn't mean you have to do it. In this step, you want to seek out creative people for possible options, the friend who is always coming up with crazy ideas. Find people outside your experience, perhaps other parents who have been through this process before. Get as many options as possible. The person you want to stay away from at this time is the person who says, "Oh, that's Black and White, there is only one option."

Once you have options in mind, you then start to prioritize them. To do this, get out your list of interests you made be-

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The art of negotiating: Dealing with problems efficiently *Cont...*

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fore. The most successful negotiations are those where everyone feels like their interests have been met. So it follows that it is easier to come to agreement on shared interest. Look at the interests you and the other party have in common, then look for options that meet those interests. These are often the most attractive options and usually very effective starting points in a negotiation.

Looking for objective standards helps add legitimacy to the agreement.

If you can say to the other party, "This isn't what I'm saying, this is what experts say," they are much more likely to listen. If you can find independent data on which both you and the other party can base your agreement, both sides are much more likely to be satisfied with the end result. Remember, "Data is Power," and if you have lots of data to back up your options, then it will be much harder for them to disagree with you. This is especially useful when there is a large power differential between the parties. When you find a standard you think you and the other party can agree on, write them down.

Where do you find these Independent data? This Foundation is called the VCFSEF Educational Foundation. Everything you learn here is ripe for use in negotiations. The Internet is another huge source of information. There are parents support groups, chat rooms, medical journals, newspapers, university libraries all with legitimate, independent information to rely on for objective standards. If you don't have the Internet at home, try the library, or the local Internet café. Local community colleges or computer stores offer great classes to help you access this information.

The law can also provide standards to shape an agreement. If there are minimum requirements for care of your child, you should know these and have them available. If there are policies and procedures for your school district, insurance carrier etc... learn as much as possible so that they can be used to structure an agreement.

Once you have done all your homework, have your interests in mind, have a list of options to offer, and have objective standards to back up your options. Now you are ready to sit at the table.

When you're at the table:

Interests – Be prepared to share your interests and be open to theirs. If they know why you want what you want the other party is more likely to work to get it for you.

Conversely, even though you have thought about their interests, there may be other factors that influence their thought process of which you are unaware. Be prepared to ask why they are taking a particular position, and listen to the answer.

Options – Date your options, don't marry them. Sometimes when you put a lot of work into an idea, you become attached to it, like it is your child. The purpose of brainstorming is to increase the number of options, so if you stick to the ones you have when you walk in, you are defeating the purpose. Have options available, but be creative and open to participating and developing new ones as you negotiate.

Standards – Shield and sword, not bomb. Be careful not to overwhelm the other party with data. Arriving at a meeting with a file cabinet on your back is the quickest way to turn off the other party (bomb). Instead, summarize the contents and provide the source. It is much more accommodating to arrive at a meeting with a small folder rather than boxes of information. Then use the data to back up your points (shield) and to question options you disagree with (sword).

Memorialize – When you are done, write the agreement down. Explain that this is not a matter of trust, but to minimize any future misunderstanding about the agreement. If only a partial agreement is reached, write the things you agree on, then list the items on which you are still negotiating. Every one signs it, every one gets a copy, and everyone feels like they have had a part in the process.

When all else fails, Mediate – If you come to an impasse, suggest a neutral third party might help get things going again. Most communities have a dispute resolution service for minimal cost where trained mediators can help parties manufacture agreements.

References:

Fisher, Roger and Ury, William. *Getting to Yes: Negotiating Agreement Without Giving In*. Boston: Penguin Books, 1981.

Fisher, Roger and Ertel, Danny. *Getting Ready to Negotiate*. New York: Penguin Books, 1995.

Coby J. Anderson, J.D. teaches mediation at both Thomas Jefferson School of Law and California Western School of Law in San Diego, California. He is also co-founder of Communication Partners, a private firm offering mediation, facilitation and training in conflict resolution to the healthcare industry.

Linda L. D'Antonio, Ph.D. is a Speech-Language Pathologist and Professor of Surgery at Loma Linda University, California. In response to her 30 years of clinical practice in healthcare she has turned her research interest to the study of conflict in healthcare. She now provides mediation, facilitation and training in conflict resolution.

New board elected

A new Board of Directors was elected at the general membership meeting held on Friday, July 23rd, 2004. Congratulations to Nancy Robbins, a past Council member who was elected President. Thank you to Monica Townsend-Mervin, who just completed her term as President for all her hard work, especially in organizing a fabulous Kids' Camp at the Atlanta conference. Following the membership's unanimous vote approving a change in our By-Laws, the position of Secretary-Treasurer was divided into two separate posts. This was necessitated by our growth as an organization. Lisa Jennings will continue as Treasurer, and Carrie Heran was elected Secretary. Raymond Tanner joins Council as a lay member until 2006, completing a term that was vacated unexpectedly last year, and Jeff Landsman was elected to the lay council position (2004-07) to succeed Linda Opper, who completed her three-year term. Stephan Eliez completed his term as professional council member and Doron Gothelf was elected to serve until 2007. Many thanks to Stephan and Linda! The Complete list of board members and Committee Chairs and their email addresses is included below. Please feel free to contact any one of us with suggestions or questions, or to volunteer your time and talent!



Newly elected president Nancy Robbins (left) shares a smile with Executive Director Dr. Kushner.

VCFS Educational Foundation, Inc. Board for 2004-05

Executive Director:

Karen J. Golding-Kushner (2007): kgkushner@vcfsef.org

President: Nancy Robbins (2005): nirobbins@aol.com

Treasurer: Lisa Jennings (2007): LisaMJenn@aol.com

Secretary: Carrie Heran (2007): vcfsparent@aol.com

Newsletter Editor: Eileen Marrinan (2006):
MarrinaE@upstate.edu

Council

Lay Members:

2005: Fred Berg: fredb1411@msn.com

2006: Raymond Tanner: tanner@arcom.com.au

2007: Jeff Landsman: jlandsman@wheelerlaw.com

Professional Members:

2005: Wendy Kates: katesW@upstate.edu

2006: Jay Riski: John.Riski@choa.org

2007: Doron Gothelf: gothelf@stanford.edu

Ex-officio:

2005 Past President: Monica Townsend:
mtownsend@peoplepc.com

Past Executive Director: Bob Shprintzen:
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Committee Chairs

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Publications: Nancy Robbins: nirobbins@aol.com

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Membership: Wendy Kates, Fred Berg

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2005 Conference:
July 29-31
Syracuse, NY

Images from Atlanta 2004



Standing room only at the 10th Annual conference in Atlanta



Dr. Doron Gothelf addresses the room at the 10th annual conference in Atlanta.



Representatives of the European Federation of the VCFS Educational Foundation, Inc.



New friends at Atlanta "Kid Camp".



Surgery for Speech panel

Do you have Desktop Publishing Expertise ?

VCFSEF Inc. seeks volunteer(s) with desktop publishing expertise to assist in producing the VCFSEF Newsletter. Knowledge of Microsoft Publisher 2003 or above will continue compatibility with current system, but if you can offer a better mouse-trap; we'll listen.

Interested? Please contact Eileen Marrinan at marrinaE@upstate.edu.