



VCFS Magazine

VCFS and 22q11 Foundation
Families and Professional caring for people with
Velo Cardio Facial Syndrome/Shprintzen Syndrome/Di George Syndrome
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Presidents Report

Behind the scenes your board has been busy organising the 2009

- VCFS Conference Day
- VCFS Awareness week
- VCFS Awareness Walk

The Conference is in the same place at the Children's Hospital Westmead but is a week earlier than previous years. Sunday 23rd August starting at 9am. We have brought the conference forward a week to start our Awareness Week and we hope you all enjoy this year's new format. "A proactive approach" is the theme of the day. The agenda will be posted on our website before the day so you can choose the sessions that are relevant to you. We are aiming to book speakers relating to younger children in the morning session and those speakers talking about issues relevant to older VCFS individuals in the afternoon session. Everyone is welcome for lunch and that way we can still have a chance to catch up.

While everything we do is striving for increased awareness, Awareness Week is our chance to really get our message across. We have been ordering merchandise all branded with our logo and mascot. There are awareness packs for everyone to arrive shortly but getting in early to book stands at shopping centres or local early childhood clinics is always a good idea. Our Pink and Blue Day is again a feature of this week and asking your local schools and preschools to support this event helps raise awareness while also giving the kids a fun day. Stay on the lookout for your packs which are full of fun ideas on how you can become more involved in raising VCFS awareness.

Our Walk is the main event of Awareness Week. We have a large area booked at Parramatta Park. Rides, a mobile zoo, sausage sizzle, race car are just some the features of the day. It will be a family friendly fun day where we can all come together – wearing our pink and blue of course! Pre-registration for the day is essential and can be done on our website. Please encourage all your family and friends to join us and help make this a success. We are of course in need of helpers for the day so please contact me if you are able to help out.

Even though we are concentrating on our upcoming events don't forget to utilize the support networks we have set up for you. The online support network is up and running on our website. If you would like your profile added or have forgotten your login details please contact Maria. We also have our facebook group that is continuing to grow. If you would like more pamphlets sent out to help you explain to friends or family about VCFS we will happily send you more – just send an email. Even giving another handful to your doctor might remind them about VCFS!!

Our foundation is a strong supporter of research. If you haven't already signed up for the Newcastle Study with Dr Linda Campbell then please consider doing so. The more research there is about VCFS the greater the chance of help and support for our children.

I look forward to seeing everyone shortly at our upcoming events.
Melinda Woods
President

VCFS 22q11 Foundation CALENDAR

- AGM and Conference Sunday 23rd August 2009 at 9am. RSVP Lucy (02) 9984 7669 or email secretary@vcfsfa.org.au
- VCFS Awareness Week 24th-30th August

Kobe Lance was born at 35 weeks on 18.4.06, weighing 1640g, (doubling his elder sisters’ birth weight, to the gram). Delivered early due to my sudden onset of pre-eclampsia reoccurring once again in my second pregnancy. Our initial goal was for Kobe to gain weight in order to have enough strength to be able to suck all his feeds, this was a slow process balancing breast feeding, nasal gastric tube & the bottle. During his time in the nursery he had to undergo an operation for his bilateral inguinal hernia. Kobe stayed in the nursery for 39 days before being discharged. His hernia & his continual struggle to thrive was one of several anomalies that he developed from VCFS which was not diagnosed until he was 18 months of age.

Kobe was weighed on a regular basis which has only eased at the age of 22 months, a lot of trial & error on what would be best for him to enable him to thrive, transferring to formula feeds was our first step. At 15 months he was referred to a gastro specialist, leading to various medical tests.

The continual increase of his head circumference was another area which was being closely monitored resulting in a Head Ultrasound which proved to be a normal result, this condition is also hereditary on his mums side with no medical ill effects. At 17 months he was referred to a neurologist for an assessment, which led to more tests with another positive outcome. Kobe struggled to raise his head, this was not achieved until 17 months and only for a half a minute, the weight/size of his head contributed to his delay in motor skills. At 13 months he commenced physio & continues to benefit from these sessions, Kobe crawled (bunny hopped) at 19 months & now furniture surfs!(as from 23 months)

At 7 months Kobe was admitted into hospital due to a respiratory tract infection, this was the first of his many respiratory illnesses in which still continue today, unfortunately requiring hospital care 3 times. Upon the third admission at 16 months, many doors were opened & decisions made, I resigned from work after 16years with the one company. We were referred to a genetic doctor to investigate the underlying issues associated with his chest problems & failure to thrive. Concluding the last hospital admission he was also sent home with a nasal gastric tube to assist in the weight gain lasting over a period of just over 2 months this was a success. At 18 ½ months he reached his goal of over 9500g, weighing 9680g.

At 17 months we met with a genetic specialists, the feedback during the initial meeting was unfortunately that they did not believe that he had a syndrome of any kind. Tests were carried out to rule out a genetic syndrome, though this came back positive. At 18 months of age we received a phone call from the Genetic doctor to confirm that Kobe did have Velo-Cardio-Facial Syndrome (VCFS) also known as 22q11 Deletion. We have been given a diagnosis! Relief. After continual visits to medical specialists & test after test it was a relief to be able to have a name given to his condition & work forward with Kobe. This diagnosis has resulted in a whole range of other tests to be performed, ie heart & cleft palate have both returned a great result. His hearing tests led to grommets due to poor drainage and he now is the process of being fitted for a hearing aid due to failing his high frequency test.

Kobe has commenced the New Year with Learning Links in which we have both learnt new ways of communicating & playing.

Kobe’s present issues in which we are managing on a daily basis are constipation, avoiding the common cold, sleeping (we have a routine to get him to sleep during the day & night which works, unfortunately the nights can be an unsettling period). At 14 months Kobe said ‘mum’, unfortunately no other words have been spoken. He is working with a speech pathologists along with a Dietician. Kobe gags when eating lumpy food & refuses to accept finger food, very happy to take puree food from a spoon, though at 23 months he bit into a biscuit for the first time & continues to have one bite & throws the remainder away, we are slowly progressing. Weaning off a teat bottle is another challenge - refusing all toddler cups & many other varieties that have been trialed.

At 2 years Kobe was assessed at the Kogarah Diagnostic Assessment service, this has put us in touch with specialists and other education facilities that can help Kobe develop.

We are very proud of Kobe with his patience & mannerism going from one doctor/specialist to another. He is a very beautiful, happy, handsome boy whom adores his elder sister Gemma, in which she also thrives on teaching him makaton. Kobe loves the water, throwing and catching balls, opening & closing doors & climbing stairs.

Everyday we can see that he is trying to communicate & interact a lot more. We are looking forward to his future.

Tanya, Jeremy, Gemma & Kobe Jarvis

Do you like reading our family stories?

Well, our supply is drying up fast, so send us [your](#) story and a photo and we can continue to publish them in our magazine.

Please send them to editor@vcfsfa.org.au

All new stories sent will receive a voucher to the Australian Museum - Editor ☺

Please take a moment to read this message.

We are currently compiling a unique new publication which will be tremendously helpful to parents and professionals alike.

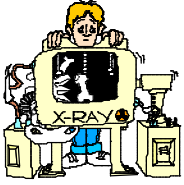
The Special Needs Handbook is a practical, easy to use problem solving guide of suggestions and tips for parents, carers and professionals encountering day to day issues.

We are compiling all the good ideas and practical solutions to everyday problems that parents and therapists have tried and tested over the years together in one publication. Once compiled, the book will be made available free over the internet, with the possibility of publishing it (not for profit) and making it available through shops.

We need your help!

We are asking as many people as possible to please send us at least one tip (or more if possible ...) to:

helen@specialneedshandbook.com



MEDICAL MATTERS

The History of the 22q11.2 Deletion by Donna M. McDonald-McGinn, M.S. and Elaine H. Zackai, M.D.

What is the 22q11.2 deletion?

Well, its history is quite interesting and worth reviewing, but first we need to step back and describe some terminology, so that everyone reading this will begin on the same footing.

As you may know, a syndrome is really a collection of findings that has been seen recurring over and over again in patients. For example, one common group of associated features includes: a heart problem; an opening in the roof of the mouth (often described as a cleft palate); and a difference in learning style. Syndromes are generally named after the person or persons who first described the collection of findings. Once an underlying cause is identified, the name may be changed to reflect the specific chemical abnormality, chromosome difference, or gene change that caused the problem.

Genes are made up of a chemical called DNA and are housed on larger structures called chromosomes. Most people have 23 pairs of chromosomes (46 total), with one of each pair coming from the mother and the other from the father. Chromosomes are numbered 1 through 22; the 23rd pair are called sex chromosomes because they determine a person's sex (male or female). The chromosomes are found in every cell in the body. Cells are so small that they, and the chromosomes they contain, can only be seen under a microscope.

Since genes are housed inside the chromosomes, they can't be seen under a microscope, but they can be measured by using special "molecular" tests. A good way to think about chromosomes and genes is to compare them to a train. A train has a number of box cars just as a chromosome has a number of stripes. We can see the box cars when we look at a train, just as we can see the chromosomes and their stripe patterns when we look under the microscope. We cannot, however, see the packages inside the boxcar without first opening the door. The same is true for a chromosome - the genes are the packages inside.

When a baby is conceived with either too much or too little chromosomal material, birth problems can occur. This may include a whole extra chromosome, as in Down syndrome (an extra number 21), a whole missing chromosome, as in Turner syndrome (a missing X), a piece of material missing or extra, or a complex rearrangement of chromosomal material. When chromosomal material is missing or extra, genes are generally missing or extra. Since genes are the blueprint of the body, when they are lost or extra, the body's blueprint changes, frequently leading to birth problems and learning differences.

So again you ask, what is the 22q11.2 deletion?

People with a 22q11.2 deletion have a very small piece of chromosome 22 missing (thus it is called a deletion). The q11.2 tells everyone who works in genetics that the area missing is in a very specific spot on the "q" arm, which is also called the long arm of the chromosome. (Chromosomes are divided into two parts, the top half being called the "p" arm and the bottom half called the "q" arm.) It is very important to know the location of a missing piece of chromosomal material in order to make some general comparisons (although no two people are exactly alike), because if two children have different areas of the same chromosome missing, it would be like comparing "apples to oranges".

In 1981, Dr. de la Chapelle in France, and in 1982, Richard Kelley, M.D., along with Elaine Zackai, M.D. and Beverly Emanuel, Ph.D. at the Children's Hospital of Philadelphia in the U.S.A., found that patients with DiGeorge syndrome had a rearrangement of chromosome 22 which caused them to be missing a very small piece of chromosomal material on the long arm (q11.2) of chromosome 22. This rearrangement was able to be seen under the microscope. This piece of information is important, as you will see when you read on, because most 22q11.2 deletions are not seen under the microscope because they are too small.

Patients with DiGeorge syndrome have a collection of findings which include: a characteristic heart defect (interrupted aortic arch, truncus arteriosus, conoventricular septal defect, tetralogy of Fallot, etc.), problems with calcium, trouble with infection (due to abnormalities of the thymus gland), and occasionally a cleft palate. Dr. Angelo DiGeorge, who first diagnosed this collection of findings, was and still is an endocrinologist at St. Christopher's Hospital for Children in Philadelphia.

Over the years, Dr. Emanuel's group at the Children's Hospital of Philadelphia worked very hard to establish the fact that 25% of patients with DiGeorge syndrome had a visible deletion of material on chromosome 22 when they looked under the microscope. But they were still puzzled about the other 75% of patients with DiGeorge syndrome who did not have a visible deletion. In 1991, Deborah Driscoll, M.D., a member of Dr. Emanuel's laboratory group, detected a submicroscopic deletion of chromosome 22q11.2 in the majority of patients with DiGeorge syndrome using special "molecular" tests. This meant that although you could not see the material under the microscope, you could prove that the piece was absent by using a special DNA test called FISH (fluorescence in situ hybridization). This test works like a lock and key. The person in the laboratory has the key which lights up (fluoresces) if it finds its matching lock in the chromosomes. If the lock is missing from one of the pair of chromosomes 22s, only one chromosome 22 will light up in the area in question (q11.2), confirming that the patient is missing material on chromosome 22.

The majority of patients who had a 22q11.2 deletion, which caused their DiGeorge syndrome, did not have an affected parent; therefore, the change in their chromosome 22 was a "new mutation" in them. This was and still is important information for families, because, if the parents' chromosomes are normal, then the chance of recurrence in a future pregnancy is quite low. About 10% of the time, a parent is also affected with some medical problem like a heart defect and also has the 22q11.2 deletion. If the deletion is present, then that individual has a 50% chance of passing on the chromosome 22 with the deletion to his or her

children. The chance of having more than one child affected when the parent has the deletion is random (like the chance of flipping a coin twice in a row and finding "heads" twice in a row). When a child receives the chromosome 22 with the deletion, the medical problems can be quite variable. For example, from a very mild heart problem to a very severe heart problem or no heart problem at all.

So, what else happened in the history of the 22q11.2 deletion?

Well, backing up a bit, in 1968, William Strong, M.D., a physician from Cleveland, reported an association of cardiac abnormalities (right sided aortic arch), learning differences, and a characteristic facial appearance in four members of one family. In 1976, Dr. Kinouchi, a physician in Japan, reported a typical facial appearance specifically seen in patients with heart problems (conotruncal anomalies) and called it conotruncal anomaly face syndrome (CTAF). IN 1978, Robert Shprintzen, Ph.D., a speech pathologist from New York, described a disorder running in families where the patients had a combination of cleft palate or VPI (velopharyngeal-incompetence - the failure of the back of the palate and the throat to close the space connecting the mouth and the nose during normal speech, which causes the patient to sound like he or she has a cold), heart defects, learning disabilities, and a characteristic facial appearance. He called this condition velocardiofacial syndrome (velo means palate or roof of the mouth, cardio stands for heart, and facial stands for the typical facial characteristics seen in their patients). In 1980, Dr. Shimizu, also of Japan, noticed that there were similarities between the patients who were diagnosed with CTAF and those with DiGeorge syndrome. Dr. Shimizu described one patient known to have findings of both DiGeorge syndrome and CTAF. In 1981, Dr. Shprintzen reviewed the patients reported to have CTAF and suggested that they had velocardiofacial syndrome.

Following Dr. Shprintzen's reports of patients with velocardiofacial syndrome (VCFS for short), Tony Lipson, M.D., a geneticist from Australia, emphasized the wide variability in findings between patients and even with the same family. Dr. Lipson also suggested that patients who had a palatal problem generally responded well to treatment. He noted that since many of the findings in the patients with VCFS were subtle, that pediatricians may not suspect the diagnosis at all - leading to delay in treatment for the hypernasal speech (speech that sounds like it is coming through the nose). He made a plea for diagnosis of this syndrome as early as possible so that treatment could begin. However, there was no good test available in the newborn period - until recently.

The story continues.

In 1990, C.A. Stevens, M.D., from Utah, reported a patient with DiGeorge syndrome whose father had a cleft palate, problems fighting infection, and facial features consistent with VCFS. He proposed that all previously reported patients with a parent and child affected with DiGeorge syndrome were examples of VCFS. This followed a report by Rosalie Goldberg, M.S., from New York, suggesting an overlap of findings between patients with DiGeorge syndrome and VCFS, such as calcium problems and problems with infection. When Dr. Lipson reviewed his patients with VCFS, 6 of 38 patients had features of both DiGeorge syndrome and VCFS. Recently Drs. Weyerts and Jones from San Diego found that the medical problems seen in older patients with DiGeorge syndrome and VCFS were indistinguishable. So, in 1992, Dr. Driscoll, again at the Children's Hospital of Philadelphia, demonstrated that the vast majority of patients with VCFS had a 22q11.2 deletion. In fact, she found that this deletion was no different from that seen in patients with DiGeorge syndrome. This finding explained the reason for the overlap in clinical findings between the two diagnoses, and therefore supported the idea that these were in fact the same syndromes.

The story enlarges even further.

Since Dr. Driscoll's discovery that DiGeorge syndrome and VCFS are in fact the same diagnosis, other "syndromes" have been added to the list of diagnoses which have the 22q11.2 deletion as the underlying cause of the patients' problems. These presently include CTAF, as described by the Japanese, and one type of Opitz G/BBB syndrome. Opitz G/BBB syndrome was first described by John Opitz, M.D., a physician in Montana. The hallmark features include: hypertelorism (widely-spaced eyes), hypospadias (the opening of the penis is not at the tip), swallowing problems, and noisy breathing. These findings were extremely variable, from severe to mild, in affected family members. In 1995, Donna McDonald-McGinn, M.S. and Elaine Zackai, M.D., at the Children's Hospital of Philadelphia, reported a patient with Opitz G/BBB syndrome, without overlapping features of DiGeorge syndrome or VCFS, in whom a 22q11.2 deletion was found. In addition, they reported patients with overlapping features of the three syndromes, including a father and child, all of whom were found to have a 22q11.2 deletion. Since their report, Julie Fryburg, M.D., a physician from Virginia, and Drs. Lacassie and Arriza from New Orleans, independently reported patients with features of both Opitz G/BBB syndrome and VCFS and a 22q11.2 deletion.

So, in summary, the 22q11.2 deletion is thought to be the underlying cause of the medical problems associated with the vast majority of patients with DiGeorge syndrome, velocardiofacial syndrome, conotruncal anomaly face syndrome, and some patients with Opitz G/BBB syndrome. Furthermore, the diagnostic name which is given to a particular patient's set of findings is generally determined by the subspecialist to whom the patient presents. For example, patients diagnosed with CTAF presented to cardiology because of their heart defect. The same is true for many patients with DiGeorge syndrome who often had problems with calcium and their thymus gland in addition to their heart problems. Patients diagnosed with VCFS were usually older, presenting to the cleft palate clinic for follow-up due to a cleft palate or VPI. And lastly, patients with Opitz G/BBB syndrome often presented to the ear, nose and throat doctors due to their noisy breathing. Thus, the perception that these diagnoses were really distinct entities may ultimately be explained by the bias of each medical group's area of expertise.

We at the Children's Hospital of Philadelphia, therefore, refer to all patients with a 22q11.2 deletion by their cytogenetic name, patients with a 22q11.2 deletion (as we do in other chromosomal disorders, i.e. 4p-, 18q+, trisomy 21, etc.) which allows all physicians involved to immediately understand the cause of the problem, the recurrence risk, and the variable prognosis. It also allows physicians to compare their patients to children in the literature with the exact same thing rather than possibly comparing "apples to oranges".

22q and You

"Dedicated to Teaching, Learning, and Caring for patients with a 22q11.2 deletion"
Clinical Genetics Center - The Children's Hospital of Philadelphia

Dr Tony Lipson - Biography

Qualifications: MBBS NSW (1967) MRACP (1973) FRACP (1974)

Born: 11/1/1944

Died: 8/4/1996

Biography:

Tony Lipson was born in Sydney, the second child of Marianne, a law graduate from Prague, and Samuel, an architect, trained in Glasgow. Tony grew up in Bellevue Hill, developed a great love of the Australian bushland and participated enthusiastically in the local Boy Scout troop. He attended Randwick Boys High School and was one of the first year of students in the then new Medical Faculty at the University of New South Wales. Tony became an unusually accomplished paediatrician, his life tragically cut short when he was 52 years old, due to a complication of previous heart surgery for a congenital aortic valve defect.

In 1969, Tony's career in paediatrics commenced with a year as a resident medical officer at the Royal Alexandra Hospital for Children (The Children's Hospital, Camperdown). As a resident and registrar, until 1973, he was well known for his remarkable enthusiasm, for his uninhibited laughter and also brief periods of upright sleeping, the latter most often during clinical meetings. Tony continued his medical training at the Great Ormond Street Hospital and the Alder Hey Hospital, Liverpool, England, between 1974 and 1977. Following his appointment as staff specialist physician at the Children's Hospital, Camperdown, in 1977, he took on a number of roles, including coordinator and physician to the Limb Deficiency Clinic, physician to the Cleft Palate Clinic and physician to the Metabolic Clinic. These apparently unrelated service positions provided the stimulus for Tony to develop powerful and enduring interests in teratology and congenital abnormalities, and set the direction of his career, from that time on. Why were some children born without limbs? Were there important undescribed associations with cleft lips and palate? Tony developed a special interest in the Shprintzen Syndrome and was internationally regarded for this. He did sophisticated research on the foetal alcohol syndrome. His work resulted in over 100 publications. Via the NSW Poisons Centre, he instituted an advisory service for women exposed to drugs in pregnancy, which was exceptionally highly valued by the Poisons Centre and by those it served. No one could be found to replace Tony, in this work, after his death.

Partly because of the unusual nature of his work, and partly his nature, Tony tended to work on his own, though he had some excellent friends and collaborators both within and away from the Children's Hospital at Camperdown. Tony was a foundation member of the Australian Teratology Society, and served as Vice President in 1987 and President between 1988 and 1990. He was also a foundation member of the Human Genetics Society of Australasia, and served on its NSW Council in 1979 and 1984. He was a member of the Australian Perinatal Society, the Teratology Society of America, the Medical Science Club, the Australian College of Paediatrics, the Australian Society for Inborn Errors of Metabolism, the Australian Cleft Palate Association, and the Association of Children's Prosthetic and Orthotic Clinics.

Tony's life was complicated by some unusual difficulties. Some of his work attracted the professional jealousy of others, causing him sustained distress over the years. He had a long period of anticipation of the need for heart surgery, which he faced with great courage. Only a few of his colleagues knew he had a heart problem.

Tony was dedicated to his family and particularly to his wife, Anne, a social worker, and their three boys, Joe, David and Mat. They and his friends were his main interests away from work. His many other interests included Australian history, especially the voyages of Captain James Cook; growing and cultivating orchids and ferns, in which he developed great expertise; reading, swimming and arts-theatre, especially opera; and an enduring love of the bush.

Author: HA KILHAM

Does your child have the 22q11.2 deletion? Help us learn about pregnancies of babies with velocardiofacial/ DiGeorge syndrome.

We are looking for families interested in helping to identify early signs of the 22q11.2 deletion syndrome seen during pregnancy. This research will be conducted at Tufts Medical Center via medical chart review of pregnancies of babies with 22q11.2 deletion syndrome. To participate, your child must have confirmed diagnosis of the 22q11.2 deletion syndrome. The child must also be currently less than ten years of age. The study involves completing a questionnaire and allowing us to view the records about the pregnancy of your child which will be kept completely confidential. You will not need to have blood drawn nor do you need to be present during the chart review. Information gathered from this study may improve care of children in the future with the 22q11.2 deletion syndrome by allowing for early diagnosis, improvement in pregnancy management, and assistance in postnatal care for future families who may have a child with the 22q11.2 deletion syndrome. If you are interested in participating, or have any questions regarding this study, please contact the principal investigator, Dr. Jodi Hoffman, at (617) 636 – 7721.

This is a US study – those wishing to participate should contact Dr Hoffman directly or via her research coordinator Lindsay Riedl.

Email: lindsay.riedl@gmail.com

Food For Thought

Nutritionist and mother **Joanne Mooney*** examines the links between food and the behaviour and health problems of our children



During a talk on child anxiety that I attended recently, the presenter Emma was asked by one of the parents about the connection between diet and child behaviour. Emma was unable to answer this question as it wasn't her area of expertise but, believe me, the parent asking the question was on to something!

As a qualified Nutritionist, I know that there is a strong and direct link between the foods we serve to our children and their behaviour, sleeping patterns and general health. Unfortunately, diet is often overlooked by frazzled parents dealing with behaviour and health problems in their children, but small alterations in diet can make huge improvements in this area. Let me explain how your family can benefit from such changes.

Shelf life

OK, I understand. I'm a parent too, and shopping with kids in tow (and with limited time) isn't my idea of fun either. And I know it can be a trial to look at food labelling closely. But if your child isn't sleeping well, or has behaviour, bowel and/or digestive problems, it could be well worth spending a few extra minutes reading nutritional panels.

The sad fact is that lots of the foods on supermarket shelves are high in additives and preservatives, many of which cause all sorts of behaviour problems in children. As a rule, the fewer ingredients there are on the nutritional panel the healthier the food will be; longer nutritional panels usually mean more added preservatives, flavour enhancers and colourings.

And here's something to think about: Under current Australian labelling laws there is something known as the 5% labeling loophole. This means additives are not always declared on the labels because they may exist in an ingredient that makes up less than 5% of the product.

Those ingredients are often additives and preservatives that can cause problems for children, so if you can avoid pre-packaged foods and go for fresh, raw unprocessed foods as much as possible, you're off to a good start.



Some websites with information on nutritional panels are:

www.cfsan.fda.gov/~ear/hwm/labelm.html and www.nhlbi.nih.gov/ehd/Tipsheets/readtheLabel.htm

Two books worth reading are *Low to No Additives* and *Read the Label*.

Sweet nothings

It's not just additives that can cause problems. Many childhood behaviour problems are exacerbated by diets that are high in fat and sugar. And you might be surprised by what products have high fat and sugar content – food such as muesli bars, muffins and breakfast cereals. Check the nutritional panel and go for foods that have fat and sugars contents of less than 10 grams per 100 grams. Ensure that the majority of the fat is monounsaturated and polyunsaturated, not saturated or 'trans'.

Foods that are high in sugar... cause cortisol levels in the body to rise, which in turn results in a so-called 'fight or flight response'. This means an increase in heart rate followed by the inevitable crash, and we all know what kids are like when they hit that stage – adrenal exhaustion and fatigue set in, resulting in irritability and anger.

Simple carbohydrates, which include added sugars and natural sugars found in fruit and milk, are often listed on food labels as carbohydrates. Children should get most of their energy from complex carbohydrates rather than those that contain sugar.

Foods that are high in sugar not only decrease amounts of vital B vitamins in the body, they also cause cortisol levels in the body to rise, which in turn results in a so-called 'fight or flight response'. This means an increase in heart rate followed by the inevitable crash, and we all know what kids are like when they hit that stage – adrenal exhaustion and fatigue set in, resulting in irritability and anger. High sugar consumption also affects neurotransmitters in the brain, and can interrupt sleep cycles – leading to a tired child and therefore tired parents.

Can the caffeine

Many parents enjoy a cup of coffee and piece of chocolate, but these foods are definitely not suitable for children. Trust me, remove products containing caffeine (such as chocolate, cola, energy drinks and so on) from your child's diet and you'll be glad you did.

Caffeine consumption increases cortisol levels, raises blood pressure, increases anxiety and impairs sleep.

It really helps if you don't model negative eating behaviours for your children. They see and learn from everything we do, and if they think mum and dad get energy from a latte and a piece of chocolate cake, and wind down with alcohol and a bag of chips, they can't be expected to avoid these things as the years roll on. Yes, marketing and peer pressure has a role to play in all this, but parents have the most influence on their children's dietary beliefs and behaviours. Eating patterns are established early on in life and if parents don't have the time or inclination to prepare wholesome and nutritious meals – and eat such food themselves – children can get locked into damaging dietary regimes that are extremely hard to break.

Here are some simple ideas to start with:

- Homemade frozen yoghurt
- Muesli slices
- Vegetable rice-paper rolls
- Carrots and celery with hummus
- Tuna or chicken sandwiches with cottage cheese and alfalfa
- Salad sandwiches
- Lentil balls
- Bean nachos with avocado dip
- Fruit smoothies with yoghurt
- Wholemeal pancakes with stewed fruit
- Boiled eggs
- Frittatas
- Wraps with hummus and vegies
- 4-bean mix with tuna and salad

... the list goes on (and I'd be more than happy to provide parents with more ideas).

Introduce new and exciting foods, and create dishes that are colourful and pleasing on the eye. Create tasting plates from which children can pick out food that they haven't tried before. Get the kids involved in preparing meals. Read and learn about the countries that the food has come from – maybe hold country-themed nights. Plant a vegetable garden and get the kids involved in the watering and feeding the veggies. Get creative!

Make the change

If you alter your child's diet in the ways I've described, it's quite likely that you will notice improvements with sleeping, behaviour and/or digestive problems within a week. If there are no obvious changes, your child could have an allergy or intolerance to a particular food that is causing problems.

Symptoms of food intolerance or allergy include rashes, sneezing, watery and bloodshot eyes, stomach ache, moodiness, hyperactivity, low energy, sleeping problems, irritability, flatulence and diarrhoea. Websites that provide information about allergies and intolerances include www.fedup.com.au, www.additivealert.com.au and www.cs.nsw.gov.au/rpa/Allergy/.

Radioallergosorbent (RAST) and skin testing that checks for food and environmental allergies can be undertaken at an allergy clinic. Food intolerances can be pinpointed with an elimination diet carried out by a qualified nutritionist.

I am happy to help parents deal with any nutritional problems. If you want to have a chat, please call me on **0417 202 861**.

*Dip. Nutrition, Dip. Remedial Massage, Dip. Sports Injuries, Dip. Aromatherapy

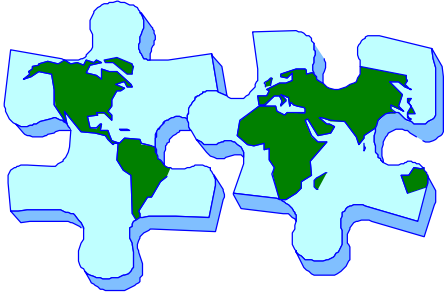
Resist the rewards

Using food as a reward for children is something to be avoided. When an adult who was rewarded with food as a child becomes depressed or anxious, they will often turn to food to give them comfort. Again, take a look at the way you use food. Do you reward or comfort yourself with sweet or savoury treats?

Don't feel you have to reward children for eating healthy food by giving them unhealthy treats. Try and make it simply part of their everyday life. Helping kids to break the junk-food habit is a challenge for parents, but the long-term benefits will outweigh the short term stresses and strains.

Low-GI ideas

Many of us feel that we don't have the time or energy to provide our kids with healthy foods at all times, so we'll often go for easy convenience foods such as chips, processed foods, soft drinks, ice blocks and lollies. But, believe it or not, creating nutritious meals and snacks for kids is easy – and it can even be fun if you get creative.



RESEARCH FROM AROUND THE GLOBE

The Prenatal Natural History of the 22q11.2 deletion syndrome

Principal Investigator: Dr. Jodi Hoffman

Co-Investigators: Dr. Diana Bianchi, Dr. Laurie Demmer, Dr. Neeta Vora, Dr. Sabrina Craigo, Ms. Lindsay Riedl

RESEARCH PROTOCOL

AIMS AND HYPOTHESIS:

Very little information has been published to date regarding the prenatal natural history of the 22q11.2 deletion syndrome and therefore the syndrome is not commonly diagnosed prenatally. We hypothesize that the currently used prenatal screening tests (such as nuchal translucency, maternal serum markers and ultrasonography) may be useful as prenatal indicators for the early diagnosis of the 22q11.2 deletion (velocardiofacial/DiGeorge) syndrome. We hope that early detection of this disease will allow couples receive more information regarding the pregnancy to improve pregnancy management and optimize postnatal care, thereby decreasing neonatal morbidity and mortality.

BACKGROUND:

In 1972, D.J.H. Brock and R.G. Sutcliffe noted an association between elevations of maternal alpha fetoprotein (AFP) levels and neural tube defects (1). In 1984, H.S. Cuckle noted an association between a decreased maternal AFP level and chromosome abnormalities, specifically Down syndrome (2). In order to allow for the prenatal detection of serious conditions such as Trisomy 21 (Down syndrome), Trisomy 18, and neural tube defects, nuchal translucency screening, maternal serum screening (MSS) and ultrasound are offered early in pregnancy. If the screening shows increased risk for one of the conditions above, amniocentesis or chorionic villi sampling can be offered for definitive testing and management.

Recently, at least three pregnancies in which maternal serum screening indicated increased risk for Trisomy 18 were found, via postnatal FISH analysis, to have the 22q11.2 deletion syndrome (3). An unpublished study of prenatal indicators in children with the 22q11.2 deletion syndrome revealed two patients with MSS markers indicating increased risk for Trisomy 18 (Lee, Kerri; personal communication). A study of 80 fetuses with normal chromosomes and excess nuchal translucency (another prenatal marker) showed no association between an increased nuchal translucency and the 22q11.2 deletion syndrome (4). Most commonly, prenatal diagnosis of the 22q11.2 deletion syndrome is due to FISH analysis performed on fetuses with complex cardiac diseases which raised suspicion for the syndrome.

Approximately 1 out of every 200 women have second trimester maternal serum screening indicating increased risk for Trisomy 18, although the incidence of Trisomy 18 is only 1:6,000 to 1:8,000 live births (5). The 22q11.2 deletion syndrome has been noted to be as common as 1 in approximately 2,500 (6). Thus, we hypothesize that it is possible that a significant portion of pregnancies with increased risk for Trisomy 18 may in fact be carrying a fetus with 22q11.2 deletion syndrome. We also hypothesize that other prenatal indicators such as ultrasound findings or pregnancy characteristics may be useful in the early diagnosis of the 22q11.2 syndrome.

RATIONALE:

The natural history of prenatal 22q11.2 deletion syndrome has yet to be studied either systematically or prospectively. Our research may support previous reports that maternal serum indicators or specific ultrasound findings may be also seen in fetuses with the 22q11.2 deletion syndrome. Early detection of the 22q11.2 deletion syndrome will not only decrease perinatal morbidity and mortality rates, but will also give families more pregnancy care options. Due to the high incidence of congenital heart disease in these patients, echocardiograms could be offered prenatally. Furthermore, physicians will know in advance to be prepared for a complicated delivery, which will ensure the child is delivered at a hospital with the availability of all necessary specialists.

EXPERIMENTAL DESIGN:

There will be two arms to this study. One arm (A) is aimed at families of live children with the 22q11.2 deletion syndrome, while the other arm (B) is a chart review of pregnancies diagnosed with the 22q11.2 syndrome which were electively terminated.

- A.** This research will be conducted through a retrospective chart review and questionnaire regarding 22q11.2 deletion pregnancies of patients from Tufts Medical Center, as well as through recruitment of families who are active on the 22q11.2 deletion syndrome parent networks. Consent forms will request permission to access the mother's records for review of prenatal and postnatal information, including: pregnancy history, outcome, and complications; nuchal translucency measurements, MSS results; fetal echocardiogram; karyotype and FISH results previously obtained via invasive procedures (e.g. amniocentesis, chorionic villi sampling), ultrasound evaluations, as well as post-natal confirmation or diagnosis of the 22q11.2 deletion syndrome.

- B. This research will consist only of retrospective chart review of patients from Tufts Medical Center who electively terminated a pregnancy of a fetus found (during or after the pregnancy) to have the 22q11.2 deletion syndrome. As it would be emotionally distressing for families to be contacted after electively terminating a pregnancy, we have requested a waiver of consent (Form VII attached) for these cases. We request permission to access the mother's records for review of prenatal information, including: pregnancy history, and complications; nuchal translucency measurements, MSS results; fetal echocardiogram; karyotype and FISH results previously obtained via invasive procedures (e.g. amniocentesis, chorionic villi sampling), ultrasound evaluations, as well as post-natal confirmation or diagnosis of the 22q11.2 deletion syndrome.

SAMPLE SIZE AND STATISTICAL ANALYSIS:

This will be a descriptive study. As MSS markers are based on multiples of the mean (MoM) from the general population (controls), an average MoM for each marker can be calculated for the enrollees and statistical significance for deviations from the mean based on sample size will be determined. We hope to identify at least 20 participants from Tufts and another 20 through support groups for arm A. We expect a smaller number of cases for arm B, as we cannot recruit for this arm.

PARTICIPANT CHARACTERISTICS:

The participants in our research will include women who carried a fetus or child affected with the 22q11.2 deletion syndrome. The child must be currently ten years of age or younger. No participants will be excluded based on race, religion, sexual orientation etc. As men cannot carry pregnancies, they are not eligible for this study. The only other exclusion criteria will be twin pregnancies, due to the difficulty interpreting the serum screen data for each fetus. Additionally, there are no circumstances in which the participant's participation will be terminated, and participants will not be excluded from participating in other research studies.

RISK/BENEFIT ASSESSMENT:

As this is a retrospective chart review study and questionnaire study, there will be no research-related injuries, or any physical, social or economic risk involved. However, there is a psychological risk factor, in that the study may cause a patient to reminisce about a difficult pregnancy or a pregnancy loss. There is also a small, but real risk of loss of confidentiality. Conversely, the benefits involved in the study include possible early diagnosis for subsequent families who may carry a fetus with the 22q11.2 deletion syndrome. Tissue banking considerations are not applicable to this research study.

SPECIFIC METHODS AND TECHNIQUES USED THROUGHOUT THE STUDY:

No new imaging, procedures, tests, or collecting of bodily components (including blood samples) will be performed. As this is a questionnaire and medical record review, no costs will be incurred to each patient family.

ASSESSMENT OF PARTICIPANT SAFETY AND DEVELOPMENT OF A DATA AND SAFETY MONITORING PLAN

We do not foresee any adverse events in this chart review or questionnaire collection. We do not feel that monitoring by a Data and Safety monitoring board would be necessary, as no interventions, treatments, or medications are being used.

PARTICIPATION:

The women who will be recruited for participation will be those identified through either Tufts Medical Center's Division of Genetics or Division Maternal/Fetal Medicine, as well as through the 22q11.2 deletion syndrome parent networks. Each of the four physician investigators, Drs. Hoffman, Demmer, Bianchi, and Craigo will be asked to provide the names of the patients known to them from their practices that had pregnancies of babies with the 22q11.2 deletion syndrome. As this is not an extremely common condition and therefore memorable, these physicians likely can recall this information (one or two such patients each year). Upon acquiring potential participant information, the research assistant will then send an introductory letter inviting participation for those to be enrolled in arm A. This letter will be followed by a phone call from the research assistant to discuss and answer questions about the research design. If the woman is interested in participating, she will be sent a consent form and questionnaire regarding her pregnancy. A stamped envelope with our address will be provided with the paperwork. Once we receive the paperwork, a copy of the consent and the questionnaire will be made and sent back to the patient. The research assistant will be able to give the participants comprehensive and specific information regarding the study, to prepare participants to provide written consent. Thus, no registration or participant transportation will be necessary, and there will be no fees incurred to the research participants for their participation. Cases for arm B will be identified by searching a the maternal fetal medicine clinical database for terms such as 22q11.2 deletion syndrome, DiGeorge syndrome, and velocardiofacial syndrome for the past ten years.

INFORMED CONSENT PROCESS AND TIMING OF OBTAINING OF CONSENT:

The research assistant will provide detailed information about the study to the participants via mail and phone, as well as obtain written consent. The principle investigator will be available to provide any necessary additional information. The research assistant will telephone each participant, who will then be given a sufficient amount of time to decide whether or not to participate. The potential participant will be assured that there will be no change in her clinical care if she chooses not to participate. The alternative to participating in this research study is to decline participation. When obtaining written consent, we will use the assumption that the legal guardian of a live child is of sound mind and has typical mental status of an adult.

STUDY PERFORMANCE LOCATION:

Participants are not required to be present at the study performance location. Information will be sent to the participants via secure fax and/or mail. The research participant's records will be kept in secure files in Tufts Medical Center's Division of Genetics.

PERSONNEL:

During the chart review and data analysis, those who will be present include Dr. Jodi Hoffman, principle investigator, and Lindsay Riedl, research assistant. Dr. Hoffman's and Ms. Riedl's proximity during the study is not relevant. Drs. Laurie Demmer, Diana Bianchi and Neeta Vora may review some of the data as well. Lindsay Riedl will have primary responsibility for obtaining informed consent, while Dr. Hoffman will be available if back up assistance is needed. Dr. Hoffman will be available to provide on-going information to the IRB. Both Ms. Riedl and Dr. Hoffman will be maintaining participant's research records throughout the study.

PARTICIPANT CONFIDENTIALITY:

We do not foresee that any part of the study will be placing patient confidentiality at risk. The only people reviewing the study will be Drs. Hoffman, Demmer, Bianchi, Vora, Craigo, and Ms. Riedl. We do not feel that the information that will be collected could have adverse consequences. An Excel file will be created that links the patient record number to their research study number. This file will be held in a file kept by the principle investigator, Dr. Hoffman. Drs. Hoffman, Demmer, Bianchi, Vora, Craigo, and Ms. Riedl will all have access to the data, including the key to the identity code, as well as access to research records. This is not a collaborative effort with another institution. As this is a retrospective chart review, no new information will be conveyed to participants. There is no payment available for participation.

OUTCOME:

The expected result will be an association or lack of association of prenatal indicators (maternal serum screen markers, nuchal translucency measurement, ultrasound, etc.) with the 22q11.2 deletion syndrome. The criteria for success will include recruitment of the appropriate number of patients to allow for statistical significance. Conversely, lack of success would include the inability to acquire the appropriate number of patients to allow for statistical significance. The end point of our study will be when the medical records of all consented patients have been reviewed and analyzed, which we believe will be approximately six months. We are hoping to publish the results of this in a peer-reviewed journal for public access to information after completion.

It all begins with you

By Maria Kamper Vice President

Having a child with VCFS has given me many more things to do in my life than I expected. Obviously as all of you would know, having a child with an issue means extra parenting, added frustration, pressure and of course an added requirement to learn more about what your child's needs are and finding the appropriate schooling, discipline and balance.

When I joined the VCFS foundation I was fairly laid back thinking that it was just about talking to others going through the same issues as me. Well I soon realised that that was not the only thing the foundation had to offer. It has given me the opportunity to give back to the community by actively participating in achieving the goals and objectives of the group, it has given me the chance of being part of something that will benefit not only my child but others who also have VCFS.

The main goal of the foundation of raising awareness has been the most difficult. This year looks positive with VCFS being put into the public domain in the USA by Quinn Bradlee. He is very fortunate that he is from a high profile family who happens to work within the media. Nevertheless it has helped bring attention to the syndrome.

Here in Australia our foundation has published a brochure, established the first VCFS awareness week, made a TV commercial seen in regional NSW and QLD as well as producing a very informative website. This is not enough though. This year we will once again have a TV commercial made, put adverts in magazines, sell merchandise during awareness week and of course hold the 1st VCFS "Walk for Awareness". My daughter's school is also assisting by holding a Pink and Blue Mufti day.

To help your child's future, your future and others affected by VCFS "**It All Begins with You**". We need you to be a part of our awareness week by coming along to our Walk for Awareness, holding your own **pink** and **blue** day or any other activity that will help raise the profile of VCFS. We will be sending out a VCFS awareness kit shortly. The kit includes ideas, information and items to help you with activities during awareness week.

I urge you all to participate where you can and help us raise awareness. Register for the walk at www.vcfsfa.org.au and see you there.

**Remember to help these events be successful and assist your family and those affected
by VCFS**

"It all Begins with You!"



Awareness Week
24th – 30th August 09

Help raise awareness?

**Wear Pink and Blue Clothes
 On 28th August 2009**

**Attend the VCFS & 22q11 Foundation
 “Walk for Awareness”
 Parramatta Park
 30th August**

Walk, Rides and BBQ

Special guest V8 Race Driver Ben Dunn with the Storage King V8 Ute

Register for the walk online @ www.vcfsfa.org.au

or fill in the form at the back of this magazine or contact our secretary
secretary@vcfsfa.org.au

Would you like to be part of ground-breaking research?

Would you like to help us better understand

Velo-cardio-facial syndrome (VCFS)?

Are you aged between 6 and 21 years?

HMRI researchers are investigating the mental health and brain function of people with VCFS. Our aim is to determine what types of difficulties people with VCFS have and why some people develop mental health problems and some do not.

You could help us investigate this!

We are looking for people who are diagnosed with VCFS.

The assessments will be in Newcastle

If you choose to come to Newcastle we will of course look after the travel arrangements and accommodation for your stay.

Give us a call if you have any questions.

Call Linda or Kate

04 15822518 or 02 49301994

Who is involved in this study?

Post-doctoral Research Fellow, Dr Linda Campbell, The University of Newcastle

Ms Kate Leadbeater, The University of Newcastle

Associate Professor Ulrich Schall, The University of Newcastle

Whats On

Adults with ADHD (NSW) Inc

Seminar dates Saturday afternoons 13th June, 12th September and 12th December 2009 2.00pm -4.30pm at North Wing, "The Muse", Sydney Inst. TAFE, Harris St., Broadway.

(Turn right when entering main gate in Harris Street.) Tea/coffee & chat afterwards
Tel: 02 9889 5977

Learning Links

2009 Workshops for Professionals, Parents and Carers

ADHD in the early years-understanding and responding (for parents and early childhood professionals)

17th June 2009 6.00pm-8.30pm at Kingsford Branch

5th August 2009 6.00pm-8.30pm at Peakhurst Branch

Cost: Non members \$65; Members \$60; Parent Members (child is enrolled in LLinks program) \$35

Ph: 02 8525 8222 for further information www.learninglinks.org.au

Relationships Australia

4th June 2009 10am-1230pm Managing Children's Behaviour

Penrith Ph: 02 47284800

Cleft Pals

National Conference Friday 3rd and Saturday 4th July 2009 and Information Day Saturday 4th July

RSVP Sonia 0425 807 489 or email brettson@optusnet.com.au

CleftPALS Victoria

2009 Events

July: National Conference in NSW

6th – 14th November: National Cleft Awareness Week

See website for updated information www.cleftpalsvic.com

CleftPALS SA (South Australia)

Morning teas-Held monthly to give parents and carers of cleft and/or palate children a chance to meet.

No obligation. Send an email cleftpals_sa@chariot.net.au or ring Leanne on 0449 751 294

Further information at www.cleft-sa.sohot.com.au

LDC

September 2009 Seminar

(For further information phone 02 9806 9960)

HeartKids NSW

Tiny Tickers Ball 2009 Saturday 1st August 2009 at the Sydney Hilton Hotel 7pm-1230pm

RSVP Friday 17th July 2009 www.heartkidsnsw.org.au

Speld NSW

Annual Conference Wednesday 7th October 2009-06-01

(For further information email: enquiries@speldnsw.org.au)

VCFS & 22q11 Foundation

24-30 August 2009-VCFS Awareness Week

For an awareness pack please contact president@vcfsfa.org.au

28 August 2009 -Pink and Blue Day

Wear pink and blue for a gold coin donation to help raise awareness of VCFS.

23 August 2009 -VCFS Conference Day

A conference for families and professionals on various issues relating to VCFS. It is held at the

Children's Hospital Westmead, Lorimer Dod's Auditorium 9am -5pm. Contact president@vcfsfa.org.au

For more details or visit our website www.vcfsfa.org.au

30 August 2009 -VCFS Walk for Awareness

Venue - Parramatta Park 11am

Wear blue and pink and walk around Parramatta Park then join us for a family picnic and some entertainment.

For a registration form go to our website www.vcfsfa.org.au

VCFS Educational Foundation (U.S.A.)

16th International Scientific Meeting, 3 – 5 July 2009, Rome, Italy

The Velo Cardio Facial Syndrome Educational Foundation, Inc.

Hosted by Associazione Italiana delezione del Cromosoma 22

Hotel Pineta Palace, Via San Lino Papa, 35 00167 Rome

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Minutes of VCFS and 22q11 Foundation Meeting 22/3/09

Attendees –

Melinda Woods, Lucy Jackson, Leanne Tye, Kim Clifton, Allison Allo, John Arena, Slade Jensen

Apologies –

Maria Kamper, Chris Thorley, Mary Thorley, Priscilla Gunton, Louise Nade

1. Minutes read and accepted by all
2. Correspondence read
3. President report read by Mel
4. Banking update given by Mel
5. Walk – Mel has park booked, rides booked, animal farm – discussed which one to book. Decided to go with Misty ridge. Mel to book. Sue Sullivan organising tables, tents and Powerade. Lou to do artwork for posters/banners. Mel to get banners organised. Allison to do media promo, press release. Still need to get a famous person. Mel talking at rotary to get them to do BBQ. All walk entries must register on line and pre-pay, need to update website to cope with that.
6. Merchandise – stickers, balloons ordered. Bags to be ordered by Lucy, hats to be ordered – Mel getting comparison quote. Other merchandise discussed e.g.: keyring, ball, stress ball, tattoos, badges, folding Frisbee, water bottle – Lucy to get quotes.
7. Media – Allison to do a press release for walk and awareness week. Everyone to use the same press release for all media. Media pack to be put together and sent out. 60 minutes still in pipeline – revisit around May. Allison going to approach Women's weekly. Will try to get local radio to do 'outside broadcast' from Walk on the day to encourage people. Using family stories important. Debate - VCFS mental health vs. broader health and learning delay aspects of VCFS to be the main focus of media campaign.
8. Awareness week – media Allison doing. Organise stands closer to week. Also doing walk, conference, pink and blue day, Allison doing a pack for pink and blue day. Need to do a count of how many booklets we have to ensure we have enough for walk and awareness week.
9. Conference – Mel to send out the standard letter for board to send out for speakers. Conference day to be structured with kid related in the morning, adolescent speakers in the afternoon. Discussed changing the way people volunteer to give more direction. People will be encouraged to volunteer for a specific role e.g., merchandise ordering, catering. A list of specific roles to be put together by Mel and added to by board.
10. Banking software – Mel to buy and send to Slade
11. Storage – The need for storage space discussed as most board members running out of space in their houses. Maria to get quote as she may be eligible for discount.
12. Books – We need to get a list of libraries together, still need to decide on what books we want, decided wait for the US dollar to get a lot better before purchasing them. Investigate funding to help support project.

Meeting closed at 12pm



REGISTRATION FORM FOR VCFS WALK FOR AWARENESS

AIM: Raise awareness for Velo Cardio Facial Syndrome / 22q11 Deletion & to have some fun doing it!

INFORMATION: **Sunday 30th August 2009**, Registration from 9am, Walk starts at 10am Parramatta Park (areas 12 & 13 see map <http://www.ppt.nsw.gov.au/map.pdf>). Parking is available inside the park.

YOUR REGISTRATION INCLUDES: VCFS Bag, Hat, Drinks bottle & PowerAde refill, kids access to petting zoo & bouncy slide

HOW TO REGISTER: Pre-registration & Pre-Payment is essential. Complete this form and return via email to secretary@vcfsfa.org.au or post to PO Box 411, Freshwater NSW 2096.

You can make payment in three ways:

- via PayPal on our website www.vcfsfa.org.au and write the receipt number down in space below or,
- complete your credit card details on this form or,
- post a cheque with your application form.

WHAT TO BRING?

Sun Screen (or an umbrella?), Comfortable walking shoes and wear a Pink or Blue t-shirt of course! We are near the Park Kiosk and there will be a sausage sizzle but feel free to bring a picnic lunch.

Individual Registration \$15

Family Registration \$25

Name: _____

Additional Family members: _____

Address: _____

Email: _____

Tel: _____ Mobile: _____

Payment: PayPal Receipt Number: _____

You can make payment through PayPal on our website www.vcfsfa.org.au home page, write down receipt number here

Cheque included or: Credit card Details: VISA Mastercard

Name on Card: _____

Card Number: _____ Expiry Date _____

How did you hear about the VCFS Awareness Walk?

Are you interested in hearing about future VCFS Activities, News & Fundraisers?

YES NO

Thank you so much for your support!