



# VCFS Magazine

VCFS and 22q11 Foundation

Families and Professional caring for people with

Velo Cardio Facial Syndrome/Shprintzen Syndrome/Di George Syndrome

Incorporated INC 9875404 ABN 22 379 450 116

Registered Charity CFN 13849



## July 2009 -VCFS & 22Q11 Foundation Awareness Week Issue

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### IMPORTANT NOTICE

VCFS & 22Q11 Foundation

"Walk for Awareness"

30<sup>th</sup> August 2009

**Change of Time**

Registration 11.00am

Walk 11.30am

Parramatta Park

### Presidents Report

August is approaching quickly and as most of you are aware this is a very busy time for our foundation. The conference day, awareness week, pink and blue day and our first awareness walk all take place and can only be successful with your help. With everyone's participation and support I look forward to this busy time being a successful campaign for VCFS awareness.

We have 9 speakers booked for the conference day. The morning is dedicated to our younger VCFS children and the afternoon topics are relevant for the adolescent/adult VCFS individuals. Even though we have divided the topics into age groups it would be wonderful if those only attending one session could still find the time to enjoy the lunch time break as it is a great chance to meet other parents. I look forward to catching up with you all on day.

Incorporated into our conference day is our foundations AGM. Without a board the foundation ceases to exist. I realise that those not in Sydney find it hard to volunteer on the board as all meetings are held at Westmead. There are however many things that can be done over the internet and are very helpful to the running of our foundation. This year to try and reduce the workload of the board we will be asking for volunteers to take on one job. Things such as being responsible for ordering merchandise, helping organise specific parts of functions such as the rides are all internet based. If you are interested in volunteering for a specific role please register your interest so I can give you more details. This is an easy way to help the foundation. Many hands make light work and that one off task that you do helps reduce the load for the board members. Thank you in advance for supporting our foundation and its initiatives.

I look forward to seeing many of you at our upcoming events.

Melinda Woods  
President

### VCFS 22q11 Foundation CALENDAR

• Next Meeting – 26<sup>th</sup> July 2009 Children's Hospital at Westmead lower ground behind the cafeteria and staff canteen 10am -12noon. RSVP Lucy (02) 9984 7669 or email [secretary@vcfsfa.org.au](mailto:secretary@vcfsfa.org.au)

• Conference and Annual General Meeting – 23<sup>rd</sup> August 2009 Lorimer Dods Auditorium- Childrens Hospital at Westmead 9am-5pm

## Jason's Story

My Name is Jason Grey and I was born 3rd December 1982. I was born with VCFS, which is short for **Velo-Cardio-Facial Syndrome**. I was born at 3:16pm at the Royal North Shore Hospital and my grandparents were waiting for me in the chapel. When I was born, my parents absolutely adored me so did my grandparents and my Aunt and Uncle.

When my family saw me, they fell in love with me at that stage of my life, during my childhood years my parent/s took me to Specialists at the Camperdown Children's Hospital of which is now called Westmead Children's Hospital.

I was in an out of that hospital when I was a child, getting prodded with needles and specialists checking me out. When I was five or six I had an operation for a Cleft Palate, as I was born without a palate. Once that was fixed, I went to Speech Therapy as my speech wasn't that great when I was young and I was still learning how to do things in life such as walk, talk, eat, wash, and dress myself.

My father, as I have been told by my grandparents and my aunt, taught me how to breathe and wash and go to the toilet and feed myself and dress myself. He also would take me to school and teach me how to use Public Transport, and take me to parties and to the shops. He would also put on birthday parties and that everyone was invited and that he would make birthday cakes and made sure that I had a great time.

When I got older my father's attitude towards me changed. My mother was in total denial once she found out I wasn't a perfect baby and had little to do with me. My parents prevented me from socializing with anyone. The only way I could socialize with people was through joining clubs like the Liberal Party and the Lions Club. If it wasn't for the Liberal Party and the Lions Club I wouldn't have met some of good friends that I still have today, that I still keep in contact with. I did also, have an opportunity with the Chamber of Commerce of which that my father was involved with meeting other people. I did get the recognition for it a lot for the work I did there and that was a good thing, but after a while it got a bore for me and I wasn't really interested in doing a lot of the things. I was just there as a person who had to tag a long and hold this and or carry this, but there was a bonus out of it though I did get to meet some people who became good friends with me.

I'm still very good friends with MRS JUDY HOPWOOD MP, MEMBER FOR HORNSBY, Judy has been a very close friend of mine as a personal friend and through the Liberal Party of NSW. Judy has also opened up some very good avenues for me in my life and workforce. I have had the opportunity to do work experience in her electorate office as a volunteer, and also became friends with her electorate staff, who work in the office. I have been involved with her campaigns. I got to be good friends with Ministers of The Federal and State Liberal Parties. And the opportunity of the Liberal Party has broadened my network of experience in the way of meeting people and helping me feel like I'm being part of the community. The Young Liberals I have been members since 2004, and they have also helped me in my local community. My friends, Matthew, Tony, Matthew and Benjamin made sure that I was comfortable and always felt welcome in the team and the family.

I have always been a community person, some people call me a humanitarian as I put my problems after every one else's. I guess, that's the way I am. I am a good, kind person with a big heart and care a lot about other people.

The person, who always loved me when she was alive, was my grandmother, Rose, who passed away in 2005. She was a beautiful woman and will remain in my heart and my thoughts for ever. Rose cared for me and made sure that I was always looked after. She was a mum to me even though she was my grandmother she and I were very close. She looked after me as if I was her son.

I adored my grandmother, Rose and I always looked forward to her visiting me and staying over at her place on the weekends and on school holidays. She took me to the movies and the opera, concerts and shows that were so spectacular.

My grandmother introduced me to the Theatre and the Arts. I have become a fan for the Arts and the Broadway musicals and the theatre if I have an opportunity I will go and see a show at the Opera house or the Lyric Theatre. My favourite Musical is Evita I was introduced to the Musical by my music Teacher Ms Byrnes, Evita has always been my favourite Musical I have the Broadway CD's and the Movie. If I ever come across a live show performance I will pay anything to go and see the Musical.

I do have good friends who are in the Performing Arts that have the same interests in the Musical Life. My friend Margaret, who I met through a day care centre in Willoughby, called Willoughby Kids House, I used to go to the day care centre before and after school and we became good friends after I left School and when Margaret retired from the Day Care Centre. I also met another friend of mine who I have known for 14 to 15 years Jody who is now the manager of Willoughby Kids House he also as been a good friend of mine, he's a President of the Mosman Musical Society and that Margaret and I always made sure that we went to a show each year, which was always a good for the both of us to catch up.

My God Father Richard, is now a retired Broadway Actor also introduced me to the Theatre as well. He was in the Broadway acting when he did the Sound of Music in 1995 he gave us tickets to go and see the show. Theatre has always been an inspiration for me and that I always enjoy it, when ever I can.

My Education has been a big toll to me, during Primary School and High School I've always been in a Support IM Class, with different children that had disabilities. The teachers where fantastic and they always helped me any way they could. Even when I attended TAFE I had support from the Disability Teachers, who where very good to me. In early 2009, I am going to complete my course in CERT II in Information & Technology; I am very looking forward in doing that course through TAFE.

I have had a difficult life, but through the help of friends, one in particular, Dave, who is now my Carer, has open the door to a new life for me where I haven't had to be afraid of life or try to end my life. Dave organizes all of my medical appointments and makes sure I meet them. Also with the support of some kind and very concerned Medical Professionals and the correct medication and specialized help by a Psychologist for the past 19months, we have achieved a lot of progress with my general health and my mental stability. When I was given the opportunity to move out of my parents' place, I weighed 32 kilograms. I now weigh 55 kilograms. I thank Dave and my very good friend, Nicole, who is like the sister I never had, who have both helped me gain a new life.

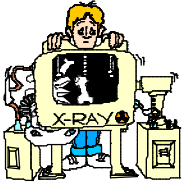
I thank them both from the bottom of my heart as they have showed me a new life that isn't part of slavery, abuse, threats or being treated like some sort of Freak that should be isolated from the general public or being used as bank. They have helped and showed me the beginning of a new life and I am so lucky to have them in my life and I know they will be with me when ever I need them. I'd like to say A Very Big Thank you.

### 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](mailto:editor@vcfsfa.org.au)

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



# MEDICAL MATTERS

## SCHIZOPHRENIA IN VCFS

An Extract from

A META-ANALYSIS OF THE PREVALENCE OF COMMON CLINICAL CHARACTERISTICS IN  
VELOCARDIOFACIAL SYNDROME

by

Dawn M. Nicotra

BS, University of Pittsburgh, 1997

Submitted to the Graduate Faculty of

Department of Human Genetics

the Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Science

University of Pittsburgh

2005

Schizophrenia is a severe and disabling mental illness with unknown etiology characterized by delusions, hallucinations and disorganized speech and behavior. It has an estimated prevalence of 1% in the general population and 25-30% in individuals with VCFS (Murphy et al, 1999; Pulver et al, 1994; and Bassett et al, 2000). Schizophrenia like many other psychiatric disorders appears to have both genetic and non-genetic factors influencing its development. Research shows that children with one parent meeting criteria for schizophrenia are 10-15 times more likely to develop schizophrenia as adults; those with two affected parents are 40 times more likely to develop schizophrenia when compared to children with normal parents (Cornblatt and Erlenmeyer-Kimling, 1985). Moreover, twin studies have shown that the genetically identical twin of an individual with schizophrenia has a 40-50% chance of also developing schizophrenia. Determining specific genetic and environmental factors would greatly increase the ability to develop appropriate treatments and/or preventive measures and initiate early intervention strategies.

Numerous independent loci have been linked to schizophrenia; some such as the linkage on 22q11.2 seem to be robust in that a large proportion of deleted individuals develop schizophrenia (Murphy et al. 1999, Shprintzen, 1992, and Pulver, 1994). A study conducted by Murphy et al. (1999) evaluated 50 adults with VCFS in an attempt to characterize the psychiatric phenotype. Once categorized, individuals with schizophrenia and VCFS (SZ/VCFS, n=12) were compared to a control group of individuals with schizophrenia but without a deletion on chromosome 22q (SZ). This study revealed that 42% (21 individuals) had a history of a major psychiatric disorder, and 30% (15 individuals) had a history of psychosis. Twenty-four percent (24% or 12 individuals) met DSM-IV criteria for schizophrenia. Six individuals with VCFS and psychosis were referred by psychiatric services thus presenting an ascertainment bias, but excluding these six subjects, the rate of psychosis remains much higher (18%) than would be expected. It was suggested that the high prevalence of schizophrenia in particular in this study might reflect a non-specific association with mental retardation since 33% of those with VCFS had mental retardation (predominantly mild). However, the rate of schizophrenia in the mentally retarded population outside of VCFS is estimated to be around 3% (Murphy et al, 1999), higher than that of the general population yet still much lower than the observed 24% in this study. Therefore, this explanation does not likely account for the increased prevalence rate observed.

Additionally, this study found a significantly later age of onset of schizophrenia in the SZ/VCFS group when compared to the SZ group. Mean age of onset in the SZ/VCFS group was 26 years whereas in the SZ group it was 19 years. Conflicting data regarding age of onset of schizophrenia in individuals with VCFS exists as other studies demonstrate an association with early-onset schizophrenia. The incidence of 22q11 deletion was examined in a series of patients with childhood-onset schizophrenia (COS). Usiskin et al. (1999) screened forty-seven patients with COS and found that three (6.4%) had a deletion of chromosome 22q11. All three individuals were said to have premorbid impairments of language, motor and social development. These results provide evidence that these deletions are in fact associated with schizophrenia and may be associated with an earlier age of onset.

There is also conflicting reports of the rates of schizophrenia in those with VCFS. In a study by Papolos et al. (1996; n=25), 64% met DSM-III-R criteria for a spectrum of bipolar affective disorders but there were no individuals meeting similar criteria for schizophrenia. Some studies have examined the rate of the 22q deletion in populations of patients with schizophrenia in an attempt to better characterize the incidence. One study by Lindsay et al. (1995) identified the deletion in two out of one hundred (2/100) individuals with schizophrenia, these individuals were not prospectively evaluated for features of VCFS. A second study (Sugama et al., 1999) screened three hundred twenty six patients admitted to a Japanese psychiatric hospital for features suggestive of VCFS, twelve were identified. Of these twelve patients, six were underwent further evaluation by FISH and one was found to have the deletion on chromosome 22. Another study by Bassett et al. (1998) assessed seventeen subjects with schizophrenia or schizoaffective disorder with two or more features suggestive of VCFS. Of these seventeen subjects, ten were found to have a deletion by FISH. Discrepancies in the published data are likely due to small sample sizes and differences in the modes of ascertainment. Most of these studies support a link between schizophrenia and a deletion on chromosome 22q11.2.

# Parenting a child with a disability: effects on a couple's relationship

By Raising Children Network

## Positive effects

Coping with the stress of raising a child with a disability can make a relationship stronger and **bring a couple closer together**. Many parents say that it is a rewarding and positive experience. It can lead to better coping skills, a stronger family, more sharing of parenting responsibilities and increased communication.

## Pressures

Caring for a child with a disability can be a lot more work than raising a typically developing child, and the extra demands can result in strain on the parents' relationship. But this isn't the only cause of stress. Other factors include:

- **Financial pressures:** transportation, equipment, medical bills and essential changes to the house can all cost a lot, and may place a financial strain on a couple.
- **Employment:** one or both parents might have to reduce their working hours to care for their child. That means less income, which is additionally stressful if costs have gone up. The parent who stays home may also feel resentful and isolated, which can place a strain on the relationship.
- **Marital roles:** when there is a child with a disability in the family, studies show that the roles of mothers and fathers tend to become more traditional, with fathers working outside the home and mothers providing primary care for the child. One or both parents might be uncomfortable with this division of labour.
- **Child behaviour:** according to research, often it's not the disability that causes most parents stress – it's any behavioural problems that go along with the disability. The type, intensity and frequency of behavioural problems can really affect your relationship with your partner.
- **Time pressures:** you might have far fewer opportunities to spend time with your partner, go out, keep up your own interests or go on holidays.

## Dealing constructively with relationship strains

**Spending time together as a couple** is the best thing you can do to reduce any strain on your relationship. Find a way to spend pleasurable time together, for both leisure activities and intimacy. You may need to take advantage of respite care to give you time alone.

Here are some other ways to reduce the strain:

- **Celebrate achievements,** your own and your child's – focus on positives.
- **Share the workload** at home so that one parent is not overburdened.
- **Talk** to each other about your feelings, listen to each other and give each other emotional support.
- **It's OK to laugh:** a sense of humour helps to lighten situations and relieve tension.
- **Claim all financial benefits** that you are eligible for in order to reduce financial strain. Make decisions together about areas where you can save money.

**Use all supports available to you.** The more support you have the less stressed you may be and the better your relationship with your partner is likely to be. Parents who have more support report greater marital satisfaction and less stress. Support can come from:

- family members
- disability associations
- community agencies
- peer support groups, such as [MyTime](http://www.mytime.net.au), ( [www.mytime.net.au](http://www.mytime.net.au) )
- professionals such as psychologists or relationship counsellors (Relationships Australia)

## Handling conflict

Conflicts and tensions occur in even the strongest relationships, so they are bound to occur when there is extra stress. The following techniques are helpful for resolving conflict:

- Listen and try to understand.
- Commit yourself to finding a solution when you have differences.
- Be prepared to compromise.
- Focus on the problem situation, not the person.
- Let your partner talk without interruption.
- Sit down while talking and do not argue aggressively or shout.

## When should I worry about my relationship?

Immediately after your child is diagnosed with a disability, your relationship may be affected while both of you adjust to the diagnosis and manage your **emotional responses**.

Every couple will deal with their child's diagnosis differently. But your relationship may need attention if some of the following behaviours persist over a period of time:

- a loss of sex drive
- not enough time for intimacy
- not enough time to spend together
- talking to one another a lot less
- having more and worse arguments.

## Who can I talk to if I am worried about my relationship?

**The first person you should talk to is your partner.** You can deal with a lot of worries by talking openly – don't be scared to talk about how you feel. But if that doesn't succeed, you may want to get in touch with a relationships counsellor or a psychologist (through the [Australian Psychological Society](http://www.psychology.org.au))

# Managing expenses when your child has a disability

By Raising Children Network

## Costs you may need to consider

The financial impact of raising a child with a disability will vary depending on the disability. The more severe the disability, the more it will cost you to care for your child.

You may need to pay for the following services:

- **a carer** for your child so you can take a break
- **modifications** to your home or car
- **medication**
- **paediatric or specialist services** provided within the private health system. If you are using the public health system you may need to pay the gap between what Medicare pays and what the service provider charges
- **home help** to care for your child or to help with housework
- **aids and equipment** (if the costs are not fully covered by the health care system).

Many therapy services, such as physiotherapy, occupational therapy or speech therapy, are free but may have long waiting lists, and if you want additional services you may have to pay

The professionals you work with can help you figure out the services you will need in the short and long term to care for your child. They may also be able to tell you where you can get financial assistance and other kinds of support.

## Tips for managing your finances

Looking carefully at your **financial situation** will put you in a good position to make sure you have enough money to cover your costs.

When you're thinking about anything to do with money:

- Budgets are really helpful. Start by keeping track of what you spend on different types of expenses for a few weeks. You may be surprised.
- Priorities for spending are also helpful – what is essential, what is not, and if there is spare income after essentials, what do you most want to spend that money on?
- A savings plan can help you set money aside for unexpected expenses.
- Knowing your entitlements and taking advantage of them means extra money in the bank.

## Information about financial support

- Centrelink can give you information about what benefits you may be entitled to.
- Disability associations can give you information about sources of funding and support available for things such as low-interest loans to purchase equipment.
- The government department that deals with disability or health in your state or territory can give you more information.
- A financial planner could also be helpful.

Other parents of children with a disability can usually offer a wealth of information and support, including advice about financial assistance.

## Personal financial advice

Financial advice helps you make decisions about your money. Good advice from an experienced, well-informed financial adviser might help you save money and become more financially secure.

Generally, the only people permitted by law to give you personal financial advice are those who work for, or represent, a financial advisory business that holds an Australian financial services (AFS) licence.

Licensed advice covers superannuation, insurance, shares and managed funds, as well as many basic banking products. Advice about loans and buying real estate does not require an AFS licence.

An advisory business that gives personal advice must:

- give personal advice that suits you
- take legal responsibility for its staff and representatives
- act efficiently, honestly and fairly
- meet standards designed to protect you against something going wrong.

## Facebook

Hi, I am a researcher at the University of Newcastle, Australia. I just accidentally stumbled across your Facebook page. I have done research on VCFS for quite a while now. However, I am at a point where I decide where to go next with our research. I thought it might be a good idea to ask what type of questions you are interested in finding out more about. Do bear in mind though that I primarily do research in psychology/psychiatry and brain structure/function. I would be useless in physiological research. No promises but it would be good to find out what parents of kids find especially problematic or perhaps what the kids/adults with VCFS themselves reckon that there is a lack of knowledge about. If you click on my picture you can send a message straight through to me rather than posting on the wall. I look forward to hear from you. All the best wishes from Linda

**Velo Cardio Facial Syndrome NSW Australia**

Common Interest - Health & Wellness

<http://www.facebook.com/>

## New Supporter Update.

I am excited to tell you that **VCFS & 22q11 Foundation** has a new high profile supporter, **Lisa Wilkinson** – television presenter and star of the Today Show on Ch 9.

Lisa began her career at a young age, working for Dolly Magazine. At age 21, she became the youngest ever editor of the magazine. After four years and almost tripling circulation, she was then appointed Editor of Cleo Magazine and went on to become International Editor-in-Chief.

Her television career began in the late 1990s when she was a regular panelist on Network Ten and Foxtel's Beauty and the Beast. During the 2000 Summer Olympics, she (along with Duncan Armstrong) co-hosted The Morning Shift on the Seven Network. In 2005, she began hosting Weekend Sunrise. Lisa began appearing on Today Show in May 2007.

Lisa is married to Peter FitzSimons, a former Wallabies rugby union player who now works as a journalist, author and radio presenter. They have three children together. (Information source - Wikipedia)

Lisa was touched by our request for her to be involved with the Foundation and has written a statement for us to post on to our website:

*"When I heard about VCFS the first thing I thought is 'Why have I not heard about this before?!'. A genetic disorder that affects as many as 1:2000, it the leading cause of cleft palate and the 2nd most common cause of heart malformations.*

*Those facts alone should have bought this syndrome into the public eye, let alone the speech, learning and immunity issues that most of the VCFS population also deal with on a daily basis. As a mother I understand the need to bring awareness to Velo Cardio Facial Syndrome. With increased awareness families can better gain access to support networks, correct medical advice and trained teachers that understand the special way that VCFS children learn and mentally develop. VCFS is a cause that I believe in."*

Lisa, along with the assistance of Ch9, has also kindly offered to help us record a Community Service Announcement (CSA) which is a TV advert that is played on free air time across as many networks as we can arrange. We currently have a wonderful CSA which has been produced by Tex Whitney of [www.texwhitney.com](http://www.texwhitney.com) and uses images of some of our children along with 'Percy Puzzle' our little mascot, to get our message out there. Tex is a friend of Maria Kampers' who has kindly donated his time and skills to our cause. Tex's CSA will be playing in the lead up to the VCFS week and we will be filming our new CSA with Lisa as soon as her schedule permits. I am sure with these two wonderful announcements it will not be long before VCFS becomes better known in the general public and medical community.

Lisa has told us that although she would love to attend our Awareness Walk with her family she has a wedding on the same weekend and is therefore unable to be there however she will try and attend future VCFS & 22q11 Foundation events if her timetable permits.

*family*

A D V O C A C Y

### After school – what then?

A workshop about navigating the post school system for families of school students with a disability in years 11 or 12 or planning ahead!

- Forestville – 28 July
- Penrith – 29 July
- Campbelltown – 30 July
- Fairfield – 31 July.

**REGISTRATION: 9:00 am—9:30 am    WORKSHOP: 9:30 am—2:30 pm**

### Planning for now, tomorrow and the future

- Ryde/ Eastwood Leagues Club – 8<sup>th</sup> August.

Presented by Jeremy Ward. The day will be of interest to families wanting to plan a long term positive and secure future for a family member with developmental disability. The day will also be of relevance for workers who are considering the role they could play in supporting families with this planning.

**REGISTRATION: 9:30 am for a 10am start, WORKSHOP: 10 am—3:30 pm**

Email: [workshops@family-advocacy.com](mailto:workshops@family-advocacy.com)

## Helping a teen who has a disability.

BY SAMHSA (United States Department Health & Human Services)

How much is enough? Parents of teens with disabilities may wonder about the best way to help these youth through adolescence. Sticking points may include what to expect, when to do more, when to back off, and how to balance the needs of other family members. Keeping these issues in mind and taking a positive approach are the keys to success as children with disabilities enter the teen years.

### Defining Terms

A "disability" means one or more permanent, major, life-altering conditions, which may be progressive or sudden and which may result from disease or injury. Disabilities include such a wide range of conditions and severity that each case must be handled individually. Yet, for all but the most severely disabled teens, a few tips can help parents deal with the challenge of a child's disability along with the rapid changes that affect all adolescents.

### Putting It All Together

A teen with a disability is still a teen. Teen life is complex - a time when children experience physical and emotional changes, an urge for independence, a new and expanded social scene, and sexual awareness. A child with a disability probably has the same interests and feelings as other youth in her age group.

You can welcome teen traits as a sign of normal growth. However, disability carries added physical and emotional hurdles involving the ability to participate, acceptance by peers, and self-image. Teens with disabilities may become stressed, depressed, frustrated, or angry with their circumstances. They may resent being ignored one minute, and then be angry if someone tries to help them the next.

### Exercising Restraint

It's easy to be overprotective - after all, you're a parent. To avoid being too controlling, talk with your teen about his/her experiences and feelings and how much help he would like as you work together to address problems. You also can find advice and personal stories at the library or on the Web.

You may be angry or even feel guilty about your child's disability. These feelings are normal, but they will not help you or your child work through a challenging and crucial time of life. If you can't set those feelings aside, talk with someone who can help you - a friend, relative, or counselor.

### Staying Positive

Aim for as much of a typical teen life as your child's disability will permit. You may have to overcome qualms about what your teen can do or should try. Give your approval to social activities and be ready to tackle dating issues.

Help a teen with a disability to project an upbeat image - open and confident. Build on a teen's strengths - encourage her to develop her interests and to join activities that draw on her talents. Help her excel, but don't limit her activities only to special classes for kids with disabilities. Be ready to step in on your teen's behalf. Ensure that teachers, youth group leaders, and caregivers treat a teen with a disability as a normal person. Promote self-advocacy. Coach a disabled teen to stand up for her rights. Start by having her talk directly with doctors, caregivers, and counselors.

### Being Watchful

Guiding your teen with a disability toward a normal, active life is great, but use the same caution that applies to other youth. Make sure your teen isn't "trying too hard" socially or being taken advantage of. Don't ignore sex and substance abuse as important issues for a teen with a disability. Be a good listener, but also ask questions, get to know his friends, and let him know what you expect of him.

As with all teens, be attuned to the mental health of a teen with a disability. Talking with a caring relative or with a faith or youth group leader can help a teen work through issues and feelings stemming from a disability. However, be prepared to enlist professional help.

### Acting Fairly

Keep in mind the needs of the brothers and sisters of a teen with a disability - they can feel ignored, jealous, or stressed. Involve them in helping and caring for a teen with a disability, but try not to overdo it. Limit siblings' tasks and give them a break. Provide one-on-one time with them - that's important!

### Conversation Starters

What do you like best about yourself?

What do you think is your greatest ability?

What would you like people to know about you?

What would you like to try to do that you haven't had a chance to try?



## Poet's Corner

'Contribute to Poet's Corner' - From next issue The VCFS & 22q11 Magazine will try to publish a poem or song every quarter. It can be something you have written or a poem that you've found comfort in or been inspired by. Please send your creative works to Lucy at [secretary@vcfsfa.org.au](mailto:secretary@vcfsfa.org.au)

# Whats On

## VCFS & 22q11 Foundation

### **24-30 August 2009-VCFS Awareness Week**

For an awareness pack please contact [president@vcfsfa.org.au](mailto:president@vcfsfa.org.au)

### **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](mailto:president@vcfsfa.org.au)

For more details or visit our website [www.vcfsfa.org.au](http://www.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

### **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](http://www.vcfsfa.org.au) or fill in form in this magazine.

## VCFS Qld

### **Saturday 22<sup>nd</sup> August 2009- The VCFS Cocktail Party: A very burlesque affair...**

7pm for 7.30 start. Venue: The Old Museum at Bowen Hills.

For more info go to [www.vcfs.com.au](http://www.vcfs.com.au)

## Family Advocacy

**After School- What then?** Workshop about what happens when a young person with a disability leaves school?

Forestville Tuesday 28th July, Penrith Wednesday 29<sup>th</sup> July, Campbelltown 30<sup>th</sup> July, Fairfield Friday 31<sup>st</sup> July.

Cost \$10pp (includes morning tea, lunch and materials) Registration 9 – 9.30am, workshop 930am – 230pm.

### **Planning for now, tomorrow and the future- 8<sup>th</sup> August 2009**

Ryde/ Eastwood Leagues Club 117 Ryedale Road, West Ryde. 9.30am registration, Workshop 10am – 3.30pm

Cost: Person with disability \$20, Family member/friend \$30, student \$50, professional \$120

Email [workshops@family-advocacy.com](mailto:workshops@family-advocacy.com) or visit website [www.family-advocacy.com](http://www.family-advocacy.com)

For more information, venue details and to register call - 02 9869 0866 or 1800 620 588 (NSW non metro only)

## Addults with ADHD (NSW) Inc

**Seminar dates** Saturday afternoons 12<sup>th</sup> September and 12<sup>th</sup> 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)

5<sup>th</sup> 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](http://www.learninglinks.org.au)

## Skills for Kids

### **20-24<sup>th</sup> July 2009: Social Skills Course-Friendship in the playground.**

Kindy – Year 4: 9 – 12pm, Year4 – Year 8 2 – 5pm Venue: Blaxland phone 02 4739 0267

## LDC

### **25<sup>th</sup> September 2009 Learning & Attentional Disorders: Implications on Neuroplasticity**

Speaker Professor Rosemary Tannock.

For further Information phone 02 9806 9960 or [info@ldc.org.au](mailto:info@ldc.org.au)

## Community Links Wollondilly

### **July 30 – Sept 24 2009: Challenging Behaviours-ADHD, OCD, CD**

Speaker Dr Steve Walker, Venue Narellan Health Centre. Contact Carmel 02 4647 4550

## CleftPALS Victoria

### **6<sup>th</sup> – 14<sup>th</sup> November 2009: National Cleft Awareness Week**

See website for updated information [www.cleftpalsvic.com](http://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](mailto:cleftpals_sa@chariot.net.au) or ring Leanne on 0449 751 294

Further information at [www.cleft-sa.sohot.com.au](http://www.cleft-sa.sohot.com.au)

## Speld NSW

### **Wednesday 7<sup>th</sup> October 2009 – NSW Conference Learning Difficulties Research- Breaking the Barriers**

Latest international research, Implications for intervention, Teachers strategies, Behaviour.

Keynote Speakers Professor Maggie Snowling and Professor Charles Hume from University of York U.K.

Venue: Swisshotel Sydney. For more information go to website [www.speldnsw.org.au](http://www.speldnsw.org.au)

Register your interest by contacting the SpeldNSW office Ph: 02 9451 9477 or email [enquiries@speldnsw.org.au](mailto:enquiries@speldnsw.org.au)

**VCFS Foundation of NSW - COMMITTEE CONTACT DETAILS****President****Melinda Woods**

Phone: (02) 9872 1516

[president@vcfsfa.org.au](mailto:president@vcfsfa.org.au)**Vice President****Maria Kamper**

Phone: (02) 9958 2578

[vicepresident@vcfsfa.org.au](mailto:vicepresident@vcfsfa.org.au)**Secretary**

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Phone: (02) 9625 3710

[membership@vcfsfa.org.au](mailto:membership@vcfsfa.org.au)**Meeting Sunday 26 May 2009****Attendees: Melinda Woods, Maria Kamper, Louise Nade, Kim Clifton, Lucy Jackson****Commenced 10.00am****Met at Parramatta Park to discuss Awareness Walk Layout:**

Plenty of shaded areas for picnics, rides and petting zoo. Toilets located close by. Need to check stroller/wheelchair access

Time of walk has changed from 9am to 11am registration, 11.30am commence walk. Maria to organise scouts to be marshals for the walk. VCFS team to wear Pink hats and t-shirts to be easily identified on the day. Melinda to check with park management if any other food vendor can attend. Looked for locations for banners to be hung.

**Discussed items that need addressing for Awareness Week in August.**Press Release – Maria has written and will distribute. Pink & Blue Packs to be sent to all financial members.

- Recipe card – Play Dough and Cupcake Recipe
- Invite on .pdf and hard copy
- Balloons
- Stickers
- Tattoos, not available in time
- Brochures
- Registration form for walk
- Idea sheet – fundraising ideas discussed:
  - Ladies morning tea– invite 5 friends and get them to invite a couple each (that have not heard about VCFS). Bring a dish!
  - Neighbourhood pink and blue cake and lemonade stall
  - Pink & Blue cocktail party
  - Mini raffle
  - Pink & Blue kindy day
  - Pink & Blue Mufti day
  - NSW & Australia Playgroup -Contact and request they participate
  - Contact our local papers & radio station and tell your story.
  - Pink & Blue pampering day
  - Lolly Jar guessing
  - Balloon Raffle
  - Pink & Blue party – invite 5 friends and get them to invite a couple each (that have not heard about VCFS). Bring a dish!
  - Make a recipe cook
  - Clothes swap party
  - Book swap party
  - Flip flop fundraiser
  - Local library display
  - ECHC display
  - Brochure
  - Karaoke night – must sing songs with Pink or blue in title or artist

**Merchandise**Lucy has ordered the following that will be delivered to Storage King, courtesy of Maria before 1<sup>st</sup> week of Aug.

- Drink bottles
- Non woven bags
- Baseball caps
- Temporary tattoos
- Percy Puzzle enamel pins with info card

Lou has designed and ordered

- Playdough/cupcake recipe cards
- A4 colouring sheets

**Meeting closed 11.30am**

## **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 11am, Walk starts at 11.30am 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](mailto: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](http://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](http://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!**

# Awareness Week

24<sup>th</sup> – 30<sup>th</sup> August 09

## Help raise awareness?

- **Wear Pink and Blue Clothes**  
On 28<sup>th</sup> August 2009
- **Attend the VCFS & 22q11 Foundation**  
**“Walk for Awareness”**  
Parramatta Park  
30<sup>th</sup> 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](http://www.vcfsfa.org.au) or contact our secretary [secretary@vcfsfa.org.au](mailto:secretary@vcfsfa.org.au)

### Local community initiatives

By now you should have received your Pink and Blue Ideas pack. The packs were intended to be a tool of inspiration, to help you think about small (or large) fun events that you could organise to raise awareness within your local community.

An easy one is contacting your local schools and daycares and request they participate in Pink and Blue day on Friday 28<sup>th</sup> August by asking the children and staff to wear a pink or blue item of clothing for a gold coin donation. You can download posters from our website or ask me for a formal letter of invite. Most schools and offices I have spoken to are happy to participate.

I thought I would mention a couple of our members who have had some fantastic ideas and put them in to action: Alta has a fourteen year old son with the deletion and has been busy organising some wonderful initiatives for raising awareness this year. Alta is holding a VCFS Awareness stall at the local shopping centre during the awareness week. For the Pink and Blue day she given her local schools some activity sheets she downloaded from our website as well as giving the schools some ideas for holding their own Pink and Blue Day events.

Alta has also asked her local hotel to come on board as a sponsor, they have agreed and by allowing her to hold a fundraising BBQ and guessing completions in their beer garden. She is currently trying to secure her local radio station to advertise her activities.

On top of all that Alta has contacted all the doctors in her local area and they have agreed to take the VCFS pamphlets and put them on the counter. She is also targeting local businesses and asking them to advertise VCFS week and Alta has made little Pink and Blue ribbon pins for them to wear. Good Work Alta!

Tamar and Jason have been a busy creating a buzz in the Wollongong area. Tamar has held a talk on VCFS at her local Playgroup and handed a lot of pamphlets out to people had not heard of it before then. In August she will be hosting a Pink and Blue Day there with lots of decorated arrowroot bickies, streamers and balloons.

Tamar has booked a day at 2 different shopping centres, where she will set up a stall with all the VCFS pamphlets and a back drop of her wonderful painting that depicts her thoughts on having a son with VCFS – it is a very good talking piece!

Last year Tamar contacted the media and got some wonderful press in her local paper, she will be doing the same this year. It was through her story that a couple of people contacted the Foundation and now those people are holding Pink and Blue Day events of their own - For Tamar and Jason, inspiring others is a big part of it too.

Jason has written a song that he has put to Tamar's paintings, photographs of their young son and snippets of information about VCFS. He already showed his class mates in a presentation at TAFE. Tamar's long term goal is to do an art exhibition about VCFS and her families experiences. She is currently sourcing interested parties to help her finance this original project. Wow, Great job guys!

Alta, Tamar and Jason are wonderful examples of what individuals can do with a little bit of initiative and a lot of passion! You don't have to do all of those things, just something as simple as a Coffee Morning at your home with a few pink and blue cupcakes and some pamphlets' to pass on to your friends, so that they too can pass on information to others that are not familiar with 22q11.

It is completely voluntary and up to you to do as much or as little as you can manage. If you need some more ideas, extra VCFS supplies or anything else please contact Lucy on 02 9984 7669 or [secretary@vcfsfa.org.au](mailto:secretary@vcfsfa.org.au).

***On our own we can make ripples, together we can make waves!***



**VCFS & 22q11 Foundation**  
Registered Charity CFN13849  
ABN 22 379 450 116  
[www.vcfsfa.org.au](http://www.vcfsfa.org.au)

**VCFS & 22q11 Foundation Conference**  
23<sup>rd</sup> August 2009 The Children’s Hospital Westmead  
Lorimar Dodds Auditorium

# Free to Members

## Conference Agenda

9.00am Registration and coffee  
9.25am President Welcome

### Session 1 – Child issues

9.30am Sarah Starr – Early speech/feeding issues  
10.05am Katrina Walsh – Clever Cat speech product  
10.40am ECIA speaker – Early Intervention services  
11.15am Sally Hibbert – VCFS Dental Issues  
11.50am Lilly Wicks – Life start  
12.25pm AGM  
12.30pm Lunch

### Session 2 – Adolescent and Adult issues

1.30pm Deborah Wolfson – Relationships Aust  
2.10pm Guest speaker IVF – PDG services  
2.50pm Kate Leadbeater – Brain research  
3.30pm Sylvia Franklin – Workfocus Aust

4.10pm President close of conference  
4.15pm Afternoon Tea

## Conference Registration

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Names of those attending: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Circle one of the following choices

**Attending :** Morning Session Afternoon Session Both Sessions

**Yes** we will require lunch / **No** we won’t require lunch

Send to: 47 Third Ave Willoughby 2068 / email to [vicepresident@vcfsfa.org.au](mailto:vicepresident@vcfsfa.org.au)

# VCFS & 22q11 Foundation

## MEMBERSHIP FORM

All members receive a quarterly magazine, contact list, can attend meetings, attend the annual conference, receive minutes and if over 18 years old have the right to vote on foundation matters and elect board members.

**Please tick**

NEW APPLICATION		RENEWAL	
-----------------	--	---------	--

**DETAILS ( Please write clearly )**

NAME			
ADDRESS			
SUBURB		POSTCODE	
PHONE	(H)	(M)	
EMAIL			
My interest in VCFS is Personal/professional	Please specify		

**AFFECTED INDIVIDUALS OPTIONAL INFORMATION**

NAME	GENDER	DOB

**Privacy of information**

Information included in this form will be made available, as appropriate, to the board of the VCFS & 22q11 Foundation for the purposes of running foundation activities and producing the newsletter. This can include publishing a birthday list, naming individuals in reports of social events or labelling photographs taken at functions. The newsletter is distributed to our membership and contact list. Please indicate below whether or not you agree to your family's details being used in these ways.

**DELETE AS APPLICABLE: (this section must be completed to activate membership)**

I **do / do not** give permission for the information provided above to be used by the foundation board in the quarterly magazine.

I **do / do not** give permission to receive fundraising materials such as raffle tickets, invitations to dinners for the purpose of fundraising.

Please **do / do not** include my details on the contact list. (The contact list is given to all financial members. Many parents have benefited from using this list to share information and experiences and arrange social activities.)

I **do / do not** give permission for the foundation to contact me on behalf of professionals researching VCFS.

Signature \_\_\_\_\_ Date \_\_\_\_\_

**ANNUAL MEMBERSHIP FEE IS \$20**

Please **enclose \$20** in the form of a cheque or money order made payable to VCFS & 22q11 Foundation or fill in credit card details below which will cover membership until **30 June 2010**.

**POST THIS COMPLETED FORM WITH PAYMENT TO  
MEMBERSHIP  
47 Third Avenue Willoughby NSW 2068  
www.vcfsfa.org.au**

PLEASE BILL MY CREDIT CARD THE AMOUNT OF..... \$20.00 ( for membership )

I WOULD ALSO LIKE TO DONATE..... ( donations over \$2 are tax deductible )

TOTAL.....

Credit Card Authorisation

Mastercard    or    Visa (Please circle)    Card Number \_\_\_\_\_

Cardholders Name \_\_\_\_\_

Signature \_\_\_\_\_ Expiry \_\_\_\_\_/\_\_\_\_\_

# VCFS & 22q11 Foundation

## BOARD NOMINATION FORM

23rd August 2009

Lorimar Dodds Auditorium,  
The Children's Hospital Westmead

To: The Chair,  
c/-

47 Third Ave Willoughby NSW 2068

I.....

of .....(address)

would like to stand for the following board position/s: (please tick)

- **President**
- **Secretary**
- **Treasurer**
- **Membership**
- **Public Officer**
- **Magazine Editor**
- **Learning Difficulties Coalition Representative**
- **General Board Member**

non board position/s: (please tick)

- **Local Area Representative**

I would also like to nominate ..... for the position of

..... should he / she be willing to stand for the position.

Date .....

Signature.....

### PROXY FORM

**(to be completed if you are unable to attend in person)**

To: The Chair,  
c/-

47 Third Ave Willoughby NSW 2068

I.....

of .....(address)

appoint .....

as my proxy vote on my behalf at the Annual Board Election to be held on 23rd August 2009.

Date .....Signature.....