



VCFS & 22q11 Magazine

October 2009

Presidents Report.

This is my first report as President. It is with pride and pleasure that I take on this role. I do have big shoes to fill though. Melinda our outgoing President has done such a magnificent job over the past 5 years; I hope that I can give as much to the job as she has.

I would like to make mention of all of our fabulous members who participated in Awareness Week. Many of you took the awareness packs and ran with many of the ideas and not only raised awareness but funds for our foundation. I have had so many great stories and emails sent to me about the campaigns and everyone was excited and happy with the outcomes. I am so proud to be a part of this fabulous group and it is wonderful to see so many of you involved.

Our conference this year was also a huge success and our new format of splitting the speakers into two sessions was positively received. I know that I took a lot away from the day and look forward to a more hopeful future for my child. It was great to see so many old and new faces on the day. The talks will be on the website shortly. The AGM was also held at the conference and I would like to welcome our new general board members Alan Jackson, Audrey Currie and Cassie Taylor as well as our Local Area representatives, Tamar Stanford - South Coast NSW, Laura Cooke - VIC, Ruth Park - Dubbo, Emma Parisi - QLD and Jason Grey- Lithgow.

The foundation made history on the 30th August holding the first ever Walk for Awareness. We had more than 300 people turn up on the day and our special guests Melinda Gainsford Taylor, Tony Issa (Mayor of Parramatta), Julie Owens MP, Gladys Berijklan MP and Ben Dunn helped open the proceedings. Israel Smith Photographers have the photos on their website, for log in details contact Lucy. The committee spent endless evenings working on the walk, so I must thank them all for their efforts in particular Lucy Jackson our passionate Secretary.

Remember to go online to see our new merchandise range. Pins, Hats and drink bottles. The Christmas Party is booked for the 13th December; see the flyer in the magazine, I hope you can make it.

Recently, Mary Thorley and I went to the launch of Genetic Awareness week put on by the AGSA. The night was entertaining and inspirational. The guest speakers were Peter Secombe (Bronze Medallist – Special Olympics) as well as James Castrission and Justin Jones who completed the world's first Trans-Tasman kayak expedition from Australia to New Zealand. Through committing themselves to achieving one of "Australia's last great first" adventures, they wish to inspire others not to be afraid of pursuing their own adventures and dreams. It made me realize that no matter who you are or whatever your challenges are you can achieve your dreams and giving up is not an option! For information about these 2 adventurers visit <http://www.crossingtheditch.com.au>

Here's to another great year for VCFS and the foundation. At our next meeting we will discuss goals for 2010 as well as planning for the Pink and Blue Ball, so please if you can come along your input is welcomed.

Once again, a huge thank you to Melinda Woods for her fantastic contribution to our foundation and VCFS.

Maria Kamper
President

In this issue

Family Story
Presidents Report
Medical Matters
Poets Corner
News
Q&A
What's On
Contact us
Kids Art Corner

VCFS & 22q11 Foundation Calendar

- Christmas Party
13th December 2009
- 2010 fundraising
dinner (TBA)
- Awareness Week
(TBA)
- General Meeting
29th November 2009

VCFS & 22q11 Foundation Inc

Families & Professionals supporting those affected by VCFS & deletion 22q11

Registered Charity CFN 13849

ABN 22 379 450 116

www.vcfsfa.org.au

Family Story



Jemma's Story

Dear VCFS Organisation,

This is my story of visiting Linda Mood Bell. My mother searched seven years ago on the Internet about "LindaMood Bell" and then she tried to contact them and asked if there was a group in Australia. The company said "no there wasn't and would keep in contact with us during the following years to let us know if they were going to have an office in Australia". Several years later, LindaMood Bell emailed my mother and said they were opening an office in Australia. My mother then contacted the Australian group of LindaMood Bell and myself "Jemma Chala" got accepted into the program. I was excited and ready to go!

A Couple of months past and it was time for my mother and I to go down to Sydney to start my new adventure! We arrived in Sydney and unpacked and the next day we where straight into the program. We were there every day from 8am till 12pm, except the last week I did 8am till 3pm. I was learning quickly and it was the best thing that ever happened to me because I can understand much more now in all sorts of English and I can now be more prepared and spell words I could never spell before. As well as being more confident in speaking in front of my class.

I thank LindaMood Bell for helping me and improving myself! You guys have done a really good job with me and Mum and I are going back to do another program at the end of the year.

Kind Regards Jemma Chala.

MUM's Story.

Jemma wrote her story by herself without my help.

Jem was an emergency caesarean birth. She had breathing difficulties and was in a crib for 2 days. She came home after 5 days in hospital. At 3 years she had an operation to correct an umbilical hernia. She now has a cute belly button so we had a lucky outcome on that.

At the end of Grade 1 I noticed she had not progressed as other children in the class had. She was not speaking clearly and could write her name but not very neatly. She repeated grade one with the introduction of a School Speech Pathologist. She also had constant colds and ear infections. She had grommets fitted once. In Grade five after years of colds and infections I had her adenoids removed (there is a limit to the amount of antibiotics a mother will feed her child). After this Jemma's speech was worse but she never had an ear infection again. I made an appointment with the head speech pathologist at the Melbourne Royal Children's Hospital. She immediately diagnosed an incompetent soft palate. The adenoids were filling part of the gap left due to the incompetent soft palate and when they were removed her speech was further degraded, as the gap was no longer filled.

Continued.....

Do you like reading our family stories?

Supply is drying up fast. Please send us your story and photo so we can continue to publish them in our magazine.

Send your story and photo to editor@vcfsfa.org.au

Become a Volunteer

Volunteering can be a rewarding job. The foundation can only continue to raise awareness with its volunteers. Contact the president at president@vcfsfa.org.au

The foundation wishes to thank the following people and companies for their support

Lithgow Community College

Lisa Wilkinson

Tex Whitney Productions

www.texwhitney.com

Storage King Ph 1800 100 700

Beautiful Soles

www.beautifulsoles.com.au

Carly Cupcake and Friends

www.carlycupcake.com

Israel Smith Photographers

www.israelsmith.com

Jemma's Story (continued)

We came back several months later for a pharyngoplasty procedure. Luckily again that was successful. It did annoy her when she has a cold and got a phlegm build up on the flap, but she seems to have grown out that as she has not complained for a year or so now. She required no further speech work after the surgery. It is a fairly invasive procedure as the surgery is located close to the base of the brain. We had 3 more weeks in Melbourne just in case there were post operation issues.

She really started to struggle at Grade 9-10. I had an appraisal done in Grade 6. I was told she had an IQ of 70 and would not be able to do Grade 12 school work. The State Primary School she attended offered no additional tuition or IEP. I had many frustrating conversations with various senior school staff, but the school was devoted to their brighter children. Funny those brighter children are now in Grade 12 will Jemma and at least 50% are no smarter than the normal average grade mark.

I spend a lot of time helping Jemma with homework and ensuring her assignments are progressing and are submitted on time. The Dec/Jan one on one tuition with Lindamood Bell was exactly what Jemma needed. The teacher's were amazed at what she could do when she returned to school at the beginning of February and I am still amazed at some of her writing and reading. Her confidence has just boomed. It was a live saver for her, as she was very down at the end of Grade 11.

I did not realise, even though with my help, she would read the words but not be understanding what she was reading. All the frustrations we had in Grade 10 with understanding what she was reading was because she could not visualise what she was reading. The LindaMood Bell "Visualising and Verbalising" program did wonders for her. She did "Seeing Stars" prior to and then in conjunction with the "Visualising and Verbalising" program for the 7 weeks we were in Sydney.

It is not cheap for the one on one, but Lindamood Bell also offers school based programs of Bronze, Silver and Gold packages. Materials and training of teachers for teaching the LindaMood Bell programs to small student groups in the school environment is provided. I tried to get Jemma's current school to purchase one of the packages, but as the budget was already allocated for this year it was declined.

Also I find teachers are sceptical and very easily categorise kids into the *CAN DO* and the *CANNOT DO* groups to make survival of that academic year a bit easier. There are exceptions and Jemma has always got better marks when she has had a teacher that put in that little bit extra effort with her in conjunction with working closely with me. When I have good working rapport with a teacher, Jemma does get higher results in her final mark. Jemma gets specific marking concessions relative to her ability due to her having VCFS. All students in Secondary schools can apply for this special consideration if they are recognised as having learning difficulties.

She does not do maths; we dropped that at the end of Grade 11. She did the lowest level maths and managed a 50% mark in both semesters of Grade 11. A lot of time and repetition was required. She mastered her times table via the KUMON program in primary school. She would not keep doing the program after her times table were complete, which I regret as I think it would have made Secondary Maths a lot easier for her.

She is in Grade 12 now. All her subjects are non-exam subjects as she does not perform well in exams. She is just coping with socialising with friends of the same age. She always carries her mobile phone and if she is not quite sure what to do when out, she phones me and I suggest a solution. E.g. should she go to a party etc. She is 18 so can go to hotels and discos. We had one experience where she was very intoxicated, but that one experience was the lesson she needed. She has not drunk alcohol from that day. She is a great kid, is over sensitive at times but generally is coping with moving into the adult world.

In summary, if I was asked to identify one item of advice that I think would make a difference for a child with VCFS it would be the following. "From day one of school, constantly monitor and work with your child's teacher/s and start programs such as KUMON and Lindamood Bell as early as possible. Never give up even if your child does not progress as well as expected. I tried tutors at home and group tutoring lessons, they did not work. So then I looked for other programs. I tried a computer program called Dyslexia and some other computer programs. They were not successful either. Also be aware of her child's IQ and capabilities, but don't let it define your child's destiny at school or in life. Also get their visual and auditory processing assessed. Jemma has deficiencies in both. Knowing this allows me to work with her in a way that allows her visual and auditory processes to be used at maximum capacity. Also don't expect all things to work as some will not. And most importantly slip the three most important words, "I love you", into conversation at least once a day." ☺

Choosing a School for Your Special Needs Child

by [Eileen Bailey](#) a writer who has been writing about ADHD for over 10 years.

As parent, we all want our children to receive a quality education. We want our children to be offered every opportunity to succeed throughout their school days. But sometimes, the local public school cannot provide children with special needs the best possible education. For some parents, the only option is to search outside of the local school district to find the best school.

When a school district is not able to provide an appropriate education, they may offer parents a choice of schools within the locality that can give children with special needs an appropriate education, at the local school district's expense. Other times, parents may simply opt to look into private schooling. No matter why parents look outside the local school district, there are a number of concerns and questions that should be addressed during the process of choosing a school.

Considerations Before Looking at Schools

Before investigating schools, whether in your area or privately, take some time to think about what you are looking for and what services you believe your child needs. Some questions you may want to consider are:

- What special needs does your child have?
- What special services are required to help your child?
- How does your child learn?
- What are some of the obstacles that interfere with your child's learning?
- Are the schools you are considering convenient for your child and your family?

This information is important to keep in mind when looking at different schools and gathering information on several different schools.

Visiting Schools

Once you have created a list of needs (and wants) based on your child's individual needs, it is time to visit schools. Keep in mind that the information you may gather when visiting a school will be biased toward the school. School personnel will, no doubt, highlight the positives of the school, showing you the reasons your child will receive the best education, while downplaying any negatives. This is their job. It is your job to dig deeper, to see beyond the sales speeches and discover both the positives and the negatives of any given school.

Specific areas to look at when visiting schools:

- What is the typical class size?
- Are your child's physical needs going to be met (for example, ramps if needed)?
- What opportunities are available for parents to be involved in the school?
- What extra curricular activities are offered?
- Is the school clean (visit the bathrooms as well as classrooms and hallways)?
- Do children move from classroom to classroom during the day or do they remain in one classroom?
- Is the principal and guidance counsellor accessible and interactive within the school on a daily basis?
- What is the general atmosphere in the school? Do children look relaxed or tense? Do teachers and administration seem tense or uptight?
- Is there room outside the school for recess? What does play equipment look like and is it in good condition?
- In addition, while you are visiting the school, watch how teachers and other school personnel interact with students. Is there an environment of patience and positive reinforcement?

Looking at Specific School Policies

Schools normally have a handbook for students that outline the policies and procedures used within the school. Ask for a copy of the handbook to take home in order to review specific policies. Some of the policies you want to pay attention to include:

- Behaviour policies. How does the school manage poor behaviour? What happens when a child hits or disrupts the classroom and learning? What are the discipline procedures and does the school administration enforce the policy?
- Parent-teacher communications. How can parents reach a teacher? Is communication easy and are teachers accessible to discuss problems or concerns on a regular basis?
- Days off and half-days. What is the school schedule? How often are half-days incorporated in the schedule and will this cause inconvenience to your family?
- Homework. Are there specific guidelines in place for homework, for example, is there a time limit on how much homework is given based on age and grade?
- Student evaluation. How are students evaluated? What are grades based on? Are projects incorporated into curriculum rather than all testing?

Based on your family and your child's specific needs, you may have additional concerns that should be addressed when you visit with a school. Being prepared ahead of time can make sure you receive the information you need to make an informed choice.

Costs

Although we would all like to think that our child's education is so important it transcends costs, that just isn't always true and many parents must take into consideration the cost of sending a child to a private school.

- Uniforms. Are uniforms or certain dress codes required? How much of a cost will this be and how easy is it to find and obtain the uniforms?
- School supplies. What school supplies are parents required to obtain. What supplies does the school provide? For example, for children in middle school, is a scientific calculator required?
- Tuition. What is the tuition? Are scholarships available and how would parents apply for a scholarship?
- Transportation: How will your child get to and from school?
- Are there additional costs associated with attending the school, such as field trip, extra supplies or costs for classroom supplies?Cont'd over

Choosing a School for Your Special Needs Child...Continued

Academics and Curriculum

Academics are certainly the most important part of education. It is important, therefore, for parents to understand not only about the specific curriculum, but also about the additional opportunities available for children to learn.

Core curriculum. What are children learning in each grade? What textbooks are used? What are children reading? Does the school have a library? If not, what resources are available?

How many computers are available for children?

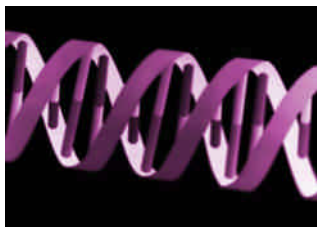
Field trips. How often are schools taken on field trips and given opportunities to integrate learning with trips to museums or other interactive learning trips?

Learning must be interactive and should be comprehensive and age appropriate.

Overall satisfaction

In addition to visiting the school, talking to personnel and gathering information on school policies, parents may want to take some time to talk with other parents. Ask the school if there are some parents that would not mind taking some time to speak with you (keep in mind these are probably parents the school knows are happy with the school). In addition, ask around to find out if other parents (not recommended by the school) would be willing to talk with you. If you know of parents that have taken their child out of the school, try to speak with them to find out why their child left the school.

The more homework you do and the more information you gather on a specific school, the more informed choice you will be able to make and the better off your child will be. 😊



Medical Matters

Feeding Tube – Infants

Updated by: Neil K. Kaneshiro, MD, MHA, Clinical Assistant Professor of Pediatrics, University of Washington School of Medicine.

Also reviewed by David Zieve, MD, MHA, Medical Director, A.D.A.M., Inc.

Often babies with VCFS have feeding issues. In many cases a feeding tube is used. A feeding tube is a small, soft, plastic tube placed through the nose (NG) or mouth (OG) into the stomach. These tubes are used to provide feedings and medications into the stomach until the baby can take food by mouth.

WHY IS A FEEDING TUBE USED?

Feeding from the breast or bottle requires strength and coordination. Sick or premature babies may not have the strength, development, or coordination to bottle or breastfeed. Tube (gavage) feedings allow the baby to get some or all of their feeding into the stomach, which is the most efficient and safest way to provide good nutrition. Oral medications can also be given through the tube.

HOW IS A FEEDING TUBE PLACED?

A feeding tube is gently placed through the nose or mouth into the stomach. It is usually taped in place. An x-ray can confirm correct placement. In babies with feeding problems, the tip of the tube may be placed past the stomach into the small intestine to provide slower, continuous feeds.

WHAT ARE THE RISKS OF A FEEDING TUBE?

Feeding tubes are generally very safe and effective. However, even if it is placed gently, a feeding tube can irritate the nose, mouth, or stomach and cause some (usually minor) bleeding. If placed in the nose, it may cause some nasal stuffiness and occasionally a nasal infection. If the tube gets misplaced and is not in the proper position, the baby may have problems with:

An abnormally slow heart rate (bradycardia)

Breathing

Spitting up

Rarely, the feeding tube can puncture the stomach.

Alternative Names: Gavage tube - infants; OG - infants; NG – infants 😊

Starting in the Workforce - useful information that may assist

1. Transition to work in NSW

Nova Transition...

Transition to Work is a NSW State Government initiative. Funded by the Department of Aging, Disability and Home Care (DADHC), 'Transition' aims to assist year 12 school leavers (who have a disability) make the move from students to employees.

To learn more about eligibility for DADHC's Transition to Work program please visit www.dadhc.nsw.gov.au - Eligibility Assessment for School Leavers.

NOVA Transition is part of a group of programs that are run by **NOVA Employment & Training Inc.** NOVA is one of the largest specialist employment agencies in Australia and since 1990 has provided job seeking and post placement support to people who have a disability.

If you'd like your son or daughter to join an outcome focused program that's fun and progressive give your local nova office a call or ring us at St Marys - 1800 656 537

Nova Employment – www.novaemployment.com.au

NOVA Employment is a community based, non-profit organisation that is funded by the Australian Government to assist people who have a disability, or permanent medical condition find and maintain the job of their dreams. To achieve this we provide a comprehensive service, assisting people to identify career goals, develop pre-employment skills, and once employed provide ongoing support.

2. Job Access- <http://www.jobaccess.gov.au/JOAC/JobSeekers>

Are you a person with disability looking for work, or an employee with disability looking for some support or assistance with your work? JobAccess provides advice on every stage of the employment process—preparing to look for work, how to look for jobs and, if you need it, support in the workplace once you've found a job.

Help for job seekers and employees

Help available

A range of services and supports are available to you as a job seeker or employee with disability. JobAccess provides details on how to access these services if you need them.

Study, training and apprenticeships

There are many services designed to support and help you access and undertake study, training or apprenticeships.

Getting work

Whether you are entering the workforce for the first time, returning after a break or just want to try something new, JobAccess has a variety of useful information that can assist you to find work.

Starting work

Got that job? You will find here a range of useful information and advice on what to consider when starting a new job.

Thriving at work

This section provides information and practical tips on how to maintain and keep your job including how to best promote yourself and increase your skills.

Returning to work

Managing a successful return to work requires some simple planning by both you and your employer. 😊

Q&A



My five year old, recently diagnosed VCFS, is about to be booked in for a pharyngoplasty and sub mucal cleft palate repair.

Does anyone have any advice on preparing a child for this kind of surgery?

(Particularly a child with limited ability to grasp abstract concepts?)

Any other experiences of this surgery would be very helpful for us to hear about.

Thanks, Fiona



- If you would like to submit a reply, please send it to president@vcfsfa.org.au
Suggestions will be published in the Parents Forum on our website www.vcfsfa.org.au

Moving Out.....from planning to action

A workshop about how you can support your family member with a developmental disability move into a home of their own with support

Who should come? Family members and friends of people with a developmental disability regardless of the level of support required. Topics of the workshop will include the planning process, housing options and exploring possible forms of support. NSW and Australian examples will be used.

November 2009 Dates and Locations: Monday 2nd-Hornsby; Wednesday 4th-Newcastle;
Thursday 5th-Burwood and Friday 6th-Wollongong.

Registration 9am-9.30am, Workshop 9.30am-2.30pm, Cost \$15 per person. Morning tea, lunch and detailed resources are included.

Register by Thursday 22nd October 2009

Phone for more information, venue details and to register on 02 9869 0866 or 1800 620 588 (freecall for NSW non metro callers) Email workshops@family-advocacy.com



VCFS & 22q11 Foundation

Christmas Party 2009

13th December

11.30am



Willoughby Park

McClelland Street, Willoughby

(Between 4th Ave and Warrane Rd)

BYO Picnic

(bbq's, bike track and fenced playground)

RSVP: Maria Kamper

By 3rd December 09

president@vcfsfa.org.au

Please let us know the names and age of children attending as Santa will be bringing gifts.



Poets Corner

This letter of support was received by the mother of a child with VCFS,
who was having difficulties with the child's school.

The mother felt that she was gaining a reputation at the school as the "mother from hell".
It was sent to her by her child's psychiatrist as a way of telling her that she was not
alone and there was a light at the end the tunnel through education and awareness.

Dear "Mother From Hell"

RE: "Your Son From Hell"

Unfortunately, the people from the flat earth society do not understand this problem because only people with wooden legs can understand what it is like to have a wooden leg. However, you and I will try to educate these difficult people so that they can understand the difficulty that you and others like you have.

***"Enlightenment
is preferable
to coercion"
- W.G.Plunkett.***



Poets Corner

If you have any
inspiring words you
would like to
contribute to the
Poets Corner, please
send them to
editor@vcfsfa.org.au

***"It's a sign of your own worth sometimes if you are hated by the right people"
- Miles Franklin***

***"Don't wait for a light to appear at the end of the tunnel,
stride down there...and light the bloody thing yourself!" -Sara Henderson***

VCFS HAS NOT STOPPED US FROM DOING ANYTHING!!!

Transcript of a speech given at the 2008 VCFS Conference by Priscilla Gunton, a VCFS mother with a VCFS child

While growing up I learnt to:

Ride a bike, a horse, played the piano, babysat children, cross country skied, tried down hill but didn't like it, drive a car, completed school, even though it was a struggle, made life long friends at school, have got a bubbly personality and am able to talk to virtually anyone – so as I said I can make and keep friends easily.

Did a secretarial course – even though on the 1st day, my original typing teacher from school saw me in the corridor and her face said it all – what on earth is she doing here! I proved her wrong and got my 50 wpm in typing and got a job in the public service! Faced many challenges in my working life in the public service, ie learnt typing on a type writer and then I had to go with the times and move on to computers. I moved inter state with my job, had a few flat mate hassles, even one flatmate leaving me with a telephone bill of \$1,000 – thankfully my dad rescued me on that one! Met my darling Peter at the work place – few months into the relationship – I took off overseas on a Contiki Tour plus a 3 week back packing experience with a long life friend – thank God she was there, don't think I could have managed the money side of it without her – budgeting wise I was fine – even came home with \$100 where as my friend came home with \$5.00. But it was the changing of the currency that confused me! And then I came home married my sweet heart produce two beautiful boys!!! And my family is complete! – Since then I have completed a computer course and finished with distinction plus I made a power point presentation on VCFS. And my typing speed improved to 70 wpm. So as you can VCFS has not stopped me from doing anything!!!!

My Difficulties

School Work I remember struggling with school particularly after Year 10 – I don't remember ever passing a test – especially maths! But no one realised I was struggling – probably due to my bubbly personality and because I wouldn't let anything get me down. I should have left school in Year 10 but didn't want to leave my friends, and my dad wouldn't have let me leave any way!

Following directions I was hopeless following more than 3 directions – still to this day I have to write down directions – or I just won't go, especially if I am by myself!

As I get older

Hip Dysplasia About 3 and half years ago I was diagnosed with dysplasia hips in both hips – eventually it will mean having hip replacements but not before I am 50 – the main restriction is that I can't put my shoes and socks on, but I do have a lovely understanding family and friends that help me when needed in that area! I am sure it stops me from catching Matthew – so watch out mate, after my weight is off and new hip replacements I will be able to catch you!

Speech Well what can I say about my speech? I do have VPI, Velo Pharyngeal Insufficiency. VPI is the INABILITY of the soft palate (the area behind the uvula or "little punching bag" in the throat) and the related muscles to close together tight in the naso-pharynx area.

When these muscles are weak or malformed they can't close off. This is when air escapes and it produces the hyper nasal speech and in most cases causes a problem with speech clarity. You may also notice that the child is unable to blow out candles or have enough force to blow their nose.

I sometimes have difficulty in getting the message across on the phone, especially names; I usually have spell them out – Gunton for example – G for Gary and so on.

But the speech hasn't stopped me from talking – My friends say I can talk under water with marbles in her mouth!

Reflections of the advantage of being diagnosed at 30

Not Overprotected I wasn't overprotected by my parents particularly by my father. If I had been diagnosed earlier I probably wouldn't have been encouraged to leave home, work, move interstate, travel etc

Achieved usual things As a mother I understand that the natural desire is to protect one's child, but I appreciate the opportunity I've had to achieve all the usual things that my friends were doing at the time.

My family Another advantage of being diagnosed later in life is that I had two glorious boys without hesitation. The only sadness here is that once I was diagnosed I decided not to have any more children.

Disadvantages for me of being diagnosed later in life

Denial By my parents that there was anything wrong with me.

No help/support Comments by well meaning friends about my speech but no constructive help was sought or available at the time.

School School was frustrating for me and the teachers – yet there was no attempt of seeking a solution.

My Health Problems

I have touched on the 1st two already, so I wont repeat myself.

Wandering Eye I have a wandering eye – its very hard to look through a telescope and stay in focus.

Bad circulation While growing up in cold Canberra, I did suffer from chilblains on toes plus my skin colour was sometimes purple!!! To this day, I have to wear socks in bed to warm up the old feet!

Heart problems Luckily I only have a heart murmur which, is nothing compared to what other VCFS kids have – so I am very fortunate!!!

Phobias: I have my fair share of phobias –

- (a) don't like (well won't!) go in lifts on my own!
- (b) Hate driving by myself to unknown areas ie like the airport.
- (c) Presenting speeches like this – hope the nerves don't let me down today!
- (d) Don't have confidence with balancing issues like carrying items down stairs, or stepping on planks to et from A to B etc.

Next Issue – Part 2: “My son, Christopher”



Photo's from the VCFS Walk for Awareness Day

Courtesy Israel Smith Photography



The Team!



Walk this way.....



Ready, Set, GO!



We would like to thank the following Pink & Blue Day Major Fundraisers and Contributors

- Sceggs Redlands, Mosman
- Castle Cove Public Schools
- Devons Meadow Primary School
- East Maitland Pre-School
- Beacon Hill Community Kindergarten
- Leighton Contractors
- The Owl & The Pussycat Pre-School, Brookvale
- Highway Childcare & Learning Centre, Salisbury Downs, SA
- Allison Allo - Idefix
- Audi Sutherland
- Christina Papadolias – Sounds Café
- Boston Corporate Holdings
- St Gerards Catholic Primary School

VCFS 22q11 Awareness Walk

Sunday 30th August 2009 was a very special day in the history of Velo Cardio Facial Syndrome or 22q11 Deletion as it is increasingly being referred to. That day saw the World's First VCFS 22q11 Awareness Walk and many of you, plus your friends and families were at Parramatta Park in NSW to support it. In fact we had nearly 350 people attend!

The Park was closed to vehicle access until 11 am, so after a

little bit of a manic start we bumped in the Storage King Super V8 Ute and set up for registration as people dressed in Pink & Blue were arriving thick and fast. While adults mingled and children got nicely 'decorated' with Percy Puzzle tattoos and pink & blue hairspray, the Scouts had arrived and started to take their places on the walk route ready to guide us all in the right direction.

Once everyone had registered and collected their VCFS merchandise, we gathered to hear the Mayor of Parramatta - Tony Issa's opening speech. He mentioned the magnitude of this being the very first VCFS Awareness Walk in the world and how pleased he was that it was organised by an Australian Charity and how proud he was that it was being held in Parramatta! The Mayor cut the ribbon being held by Maria Kamper and Melinda Woods which marked the start of the Walk. Melinda Gainsford Taylor and Benn Dunn lead the way and off we went! Everyone was pleasantly surprised that the Walk was an enjoyable Sunday stroll and not a major long distance challenge, especially for those that had young children who were not content in the pushchair and wanted to stretch their legs too!

VCFS 22q11 Foundation would like to thank all the people who participated in the 2009 Pink & Blue Day - including any fundraisers who have not been listed here.

VCFS 22q11 Awareness Walk...continued

Once we'd all made it back, the picnics began and people queued for a sausage and a nice refreshing free drink of PowerAde. Whilst we were walking the kids rides had been set up. There was a slide that was high enough to make your eyes water, a bouncy castle and a petting zoo – all where certainly the hit of the day!

The sun was shining and it was great to see everybody relaxing and enjoying them selves. I am sure everyone that was able to make it that day would say that it was a fantastic event. I know all of the children had an absolute blast and did not want the day to end.

VCFS 22q11 Foundation would like to thank all the volunteers who assisted on the day along with our wonderful supporters:

Coca Cola for providing the marquees and free PowerAde – with a special mention to the Sullivan family for organising and manning this.

The 1st East Roseville Scouts for marshalling the walk.

Rotary Club North Rocks for doing a great job on the barbie.

Eddie Harford for donating all the sausages for the event.

St Johns Ambulance.

Brett Bird from Sign King Parramatta for donating banners.

Israel Smith Photographers had been busy capturing moments through out the day which are available to view and even purchase - click on the VCFS photo in the Client Gallery at

www.israelsmith.com

And finally a big Thank You to our special guests:

Ben Dunn and the Storage King V8 Ute which was kindly brought down from Queensland by Storage King just for our event.

Veena Gollop from Bella Models.

Julie Owens MP and Gladys Berjiklian MP.

Tony Issa, Mayor of Parramatta for opening the event.

Melinda Gainsford-Taylor for promoting VCFS in the media on the lead up to the walk and for attending with her family.

And of course to all of the wonderful people that attended and made the event such a success, Thank you and we look forward to seeing you all again next time!

VCFS Conference 2009

It is always wonderful to see so many parents come together to both learn and discuss the many issues that come arise with VCFS. This year's conference was no exception. We were very lucky to again have a wonderful range of speakers. The morning session was dedicated to our young VCFS children. The speakers covered a range of topics. Sarah Starr spoke to us about early speech and feeding issues. We then heard from Katrina Walsh about her new product on the market called the Clever Cat speech product. It is a wonderful way to keep our children interested in speech therapy while keeping it relevant, interesting and most importantly fun. It makes therapy seem like a series of games. Karen Hamilton spoke to us about early intervention services. How to gain access to them and why they are so important for our children. Sally Hibbert joined us to speak about dental issues and gave the results of the study that many of our children participated in. Lilly Wicks was our final morning speaker and explained an early intervention service called Life Start. It is always wonderful to hear about the programs that can make such a difference to our children. The more knowledge we have about giving them the best start to their education the better and our morning session definitely achieved this goal.

Thank you to those who then joined us for our AGM. It is our chance to tell everyone the significant things our foundation was achieved throughout the year and to revote in our board. Thank you to everyone for participating and well done to our new 09/10 board. A big welcome to all the new faces that put their hand us to join this year. The afternoon session focused on the older VCFS individual. Geoff Holmes from Relationships Australia put things in perspective about the challenges having a VCFS child can have on a parent, the relationship between parents and the impact on the family as a whole. It gave many of us some very valid points to think about and hopefully a more positive outlook on some of the different stages we all go through. James Marshall from IVF gave us a talk about IVF options for VCFS individuals. He outlined an IVF process a VCFS person could use to have a non VCFS baby. It was informative and for many parents a relief to know that the 50% chance of passing on VCFS using this method can be eliminated. Some food for thought for many after this talk. Our final presenter of the day is one that is familiar to many of us. Kate Leadbeater spoke us about the study in Newcastle and presented some facts on mental illness and things we could do if we suspect it. She is always an entertaining speaker and was a great way to wrap up our day.

I do hope everyone enjoyed the new format of our conference day. We would love your feedback about having the two sessions focus on different age groups.

Thank you to everyone who attended and to those who helped to keep the day running so smoothly. We are a very lucky group to have so much support from the medical and allied health profession. I hope to see many of you again next year and I look forward to hearing your feedback from the day.

Melinda Woods

Contact Us



President: Maria Kamper

Ph: 9958 2578

Email: president@vcfsfa.org.au

Secretary: Lucy Jackson

secretary@vcfsfa.org.au

Membership: Mary Thorley

membership@vcfsfa.org.au

Vice President: Melinda Woods

Ph: 9872 1516

Email: vicepresident@vcfsfa.org.au

Treasurer: Slade Jensen

treasurer@vcfsfa.org.au

Editor: Chris Thorley

editor@vcfsfa.org.au

VCFS & 22q11 Foundation Annual General Meeting 23rd August 2009 The Children's Hospital Westmead

Attendees: Members attending the VCFS Conference plus Melinda Woods, Maria Kamper, Slade Jensen, Chris and Mary Thorley, Lee Tye, Priscilla Gunton and Kim Clifton

Apologies: Louise Nade, Matt Nade, Lucy Jackson, Allison Allo

Meeting opened 12.45pm

Minutes from previous meeting read and accepted by all

Presidents' report read by Melinda Woods, Melinda will be stepping down from current role of President.

Treasurers' report read by Slade Jensen.

Alan Jackson Chaired and opened the Voting in of the 2009-2010 committee

Position	Nominating	1st	2nd	Voted in
President	Maria Kamper	Melinda Woods	Mary Thorley	All
Vice President	Melinda Woods	Maria Kamper	Chris Thorley	All
Secretary	Lucy Jackson	Melinda Woods	Maria Kamper	All
Vice Secretary	Louise Nade	Maria Kamper	Priscilla Gunton	All
Treasurer	Slade Jensen	Melinda Woods	Maria Kamper	All
Magazine Editor	Chris Thorley	Priscilla Gunton	Maria Kamper	All
Memberships	Mary Thorley	Slade Jensen	Chris Thorley	All
General Board	Priscilla Gunton	Chris Thorley	Maria Kamper	All
	Audrey Currie	Melinda Woods	Slade Jensen	All
	Cassie Taylor	Maria Kamper	Melinda Woods	All
	Alan Jackson	Maria Kamper	Melinda Woods	All
Public Officer	Leanne Tye	Mary Thorley	Maria Kamper	All
Local Area reps	Tamar Stanford	Wollongong/ Sth Coast		
	Laura Cooke	Victoria		
	Ruth Park	Dubbo		
	Jason Grey	Lithgow		

Meeting Closed at 1pm

**Thank you to those families who registered for the
Sydney Special Children's Christmas Party.**

It is on Wednesday 2nd December 2009, 10am to 2pm,
Rosehill Gardens, Gate 1, Grand Avenue, off James Ruse Drive, Rosehill.
Please keep an eye out for your entry wristbands that I will post to you shortly.

Melinda Woods

Treasurers Report

Velo Cardio Facial Syndrome and 22q11 Foundation Incorporated Balance sheet as at 30th June 2009

Equity at 1 July 2008	\$ 40985.77
Increase for the year end 30 June 2009	<u>33984.56</u>
	74970.33

CURRENT LIABILITIES

Nil

This is represented by:

FIXED ASSETS

HP 2600N Laserjet Printer	459.00	357.00
Fax Machines (2)	718.00	
	<u>1177.00</u>	
Less accumulated depreciation	<u>820.00</u>	

CURRENT ASSETS

Cash available at bank	1948.73	3494.23
Prepayments - insurance	599.50	
- Walk entertainment	946.00	

INVESTMENTS

Cash on investment	71119.10	71119.10
		<u>74970.33</u>

Velo Cardio Facial Syndrome and 22q11 Foundation Incorporated Income and Expenditure Statement for the period 1 July 2008 to 30 June 2009

INCOME

Membership fees		\$ 1740.00
Donations		13366.22
Dinner 08	42424.80	
Less cost	<u>12342.17</u>	30082.63
Raffle 08		3096.00
Pink and blue day		765.00
Portrait fundraiser		175.00
Interest		<u>2119.10</u>
		51343.95

EXPENDITURE

Bank fees	15.83	
Merchant fees	920.21	
Business name rego	186.00	
Agm costs	586.71	
Stationary	1106.04	
Postage	1247.15	
Subscriptions	78.00	
Promotional merchandise	12879.50	
Website	74.85	
Christmas party	173.10	
Depreciation printer	92.00	<u>17359.39</u>

INCREASE IN EQUITY

33984.56

Treasurers Report- Continued

Velo Cardio Facial Syndrome and 22q11 Foundation Incorporated Receipts & Payments Statement for the period 1 July 2008 to 30 June 2009

Cash at bank 1/7/08		\$ 43637.27
RECEIPTS		
Membership fees	1740.00	
Donations	13366.22	
Dinner 08	40539.80	
Raffle 08	1980.00	
Pink and blue day	765.00	
Portrait fundraiser	175.00	
rebanking of bank adjustment	285.00	58851.02
		<hr/>
		102488.29
PAYMENTS		
Merchant fees	920.21	
Bank fees	15.83	
Bank adjustment see rebanking	285.00	
Insurance (period of cover 30/6/10)	1199.00	
Name registration	186.00	
Agm costs	586.71	
Dinner 08	11842.17	
Stationery	1106.04	
Postage	1247.15	
Subscriptions	78.00	
Promotional merchandise	12879.50	
Website	74.85	
Christmas party 08	173.10	
Deposits for walk 09	946.00	
Transfer to investment account	65000.00	
Transfer to investment account	4000.00	100539.56
		<hr/>
CASH AT BANK		\$1948.73

family

A D V O C A C Y

Welcomes Bob Lee to present:

Building supportive communities for people with disability

Bob Lee will draw on his many years experience to discuss the impact of the interplay between “the community” and those who are closely involved in the lives of people with disability- both family members and support workers.

Who should come? Families and extended families, allies and people who work with people with disability.

Bob's presentation precedes Family Advocacy's Annual General Meeting that starts at 1.30pm.

Phone, fax, post or email to register by Thursday 15th October 2009

Where: Ryde/Eastwood Leagues Club, 117 Ryedale Rd, West Ryde.

Registration 9.00am for 9.30am-12.30pm.

Tea/coffee on arrival, morning tea and light lunch provided.

Phone for more information, venue details and to register on 02 9869 0866 or 1800 620 588 (freecall for NSW non metro callers) Email workshops@family-advocacy.com

Cost: Family member/friend/ally/person with disability - \$10

Student - \$10; Professional \$20

What's On



VCFS & 22q11 Foundation

Christmas Party 13th December 2009. 11.30am
Willoughby Park McClelland Street, Willoughby (Between 4th Ave and Warrane Rd)
BYO Picnic (bbqs, bike track and fenced playground)
RSVP: Maria Kamper By 3rd December 09 president@vcfsfa.org.au

Adults with ADHD (NSW) Inc

Seminar dates Saturday afternoon 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

The Big Rip Guinness Book of Records attempt at tearing apart Yellow Pages" books – September/October 2009
Venue to be advised. Details on Learning Links Website www.learninglinks.org.au

LDC

Seminar- Management of Oppositional Behaviours: in the classroom and at home. Speaker Ian Luscombe, Principal.
9th November 2009 1.30-3.00pm North Shore Conference Centre UTS Kuring'gai Campus.
See website for registration details www ldc.org.au or box below.

HeartKids

Newcastle Hoe Down Saturday 7th November 2009 from 3pm. Free to HeartKids members- contact Karen.
Bexley Trivia Night Saturday 21st November 2009 Bexley RSL Club. Tickets are \$30 each- contact Karen.
Newcastle Christmas Party Sunday 15th November 10.30pm at Speers point Park, Speers Point- contact Leanda.
Sydney Christmas Party Sunday 6th December 09 10am-2.30pm Bicentennial Park Homebush Badu Shade sails site- contact Karen (Contact Details: Leanda 02 49472898 or chadlea_blackmore@bigpond.com ; Karen 0406424620 or karen.sherlock@heartkids.org.au)
Teen Camp 2010 Registrations now open for HeartKids teens 12-20 years, 22nd- 25th January 2010 at Camp Warrawee, Brisbane Cost is \$100 per attendee. Space is limited and restricted to HeartKids and siblings only.
Register online at HeartKids www.heartkidsnsw.org.au

CleftPALS Victoria

6th – 14th November 2009: 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

Family Advocacy

Friday 23rd October 2009: Building Supportive Communities for People with Disability
Ryde /Eastwood Leagues Club. Registration 9am. Workshop 9.30-12.30. Guest speaker Bob Lee.
Register by 15th October. Ph: 02 9869 0866. Email workshops@family-advocacy.com

Moving Out-from planning to action:

Hornsby-Monday 2nd November, **Newcastle**-Wednesday 4th November, **Burwood**- Thursday 5th November, **Wollongong**- Friday 6th November. Registration 9am. Workshop 9.30-2.30. Ph:02 9869 0866.
Email workshops@family-advocacy.com

Playgroup Australia Inc. The Power of PLAY Conference QLD 5-7 November 2009 Guest speakers include Governor General Quentin Bryce and leading experts on early years education and psychologists. For more information visit www.playgroupaustralia.com.au/conference



Learning Difficulties Coalition NSW Inc

Ian Luscombe, Principal

Management of Oppositional Behaviours: in the classroom and at home.

For Parents, Teachers and Health Professionals

Monday November 9th 2009,

North Shore Conference Centre, UTS Kuringai Campus, Eton Rd, Lindfield

Registration 1pm. Presentation 1.30pm followed by the AGM.

Ian has been in special education for over 20 years and principal of Redbank School for the last 7 years.

Cost \$50 non members / \$25 members Light refreshments

Register online at www ldc.org.au

Register by close of business Friday 6th November

“VCFS Kids - Art Corner”



Our first budding VCFS artist we are showcasing is Carly Nade, daughter of Matt and Louise Nade, who is 4 years old.

If you would like to show off your child's artwork, scan and send it to editor@vcfsfa.org.au or mail it to; The Editor, 19 Eleanor Crescent, Rooty Hill NSW 2766.