



VCFS & 22q11 Magazine

October 2010

President's Report

Here we are October already! VCFS has been on my mind a lot lately. Not only because we live with it every day, but because I want to be able to offer more assistance and support to all of our VCFS families and friends.

As a foundation we have done so much over the last number of years. My questions are; *-Are we supporting all those affected by what we have been doing? Are people getting the assistance they need? Do you know where to get help? Is your family suffering because of the challenges you face every day?*

One particular thing that prompted my thoughts was when one of our board members found out by accident about the Cleft Palate Dental scheme (a Medicare service).

It can be an assumption by many of us that if we know about something that can assist us everyone else would know. After this event I decided to look at our website and put information on it about services and government department links that can help our members. www.vcfsfa.org.au (Assistance and Fact Sheets)

The other thing I have been doing and so have many of our members is using *Social Media*. Social media are primarily Internet and mobile based tools for sharing and discussing information amongst our community. The most common social media being used at the moment is Facebook and Twitter. Using these types of tools has given us the opportunity to share information with each other and to connect us to other parts of the world. ***So far but so close!***

What I would like to ask of all our members, friends and families is to use these tools to share information about services that can assist us all. If you know of a service or any information that could be useful please let us know. You can do this via email, our Facebook group, Twitter or a simple phone call to one of our board members. Our numbers are on the website. Support each other in times of need. One simple word can often lift the spirits of others even if you have never met! After all a person you have never met is a friend in waiting!

As you would be aware we hold our annual conference in August. This year was fabulous and we had a great day. I want to thank all of our speakers and discussion group facilitators. The information you provided us was fantastic. I know many of you, me included went away feeling inspired after the talk by our special guest Sam Bailey. I won't talk too much about the conference as there will be a conference report in the coming pages.....*Continued.....*

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VCFS & 22q11 Foundation Calendar

- **Next Meeting**
7/11/2010 CHW
10am RSVP Maria
- **Xmas Party**
12/12/2010
Willoughby Park
from 11.30am RSVP
Louise

Support the Foundation



VCFS 22q11 Foundation
Christmas Cards
COMING SOON

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 - Christie

***“VCFS – I’m missing part of my 22
chromosome.
What’s your excuse?”***

I was born 2 weeks premature to an ambulance officer and his wife in 1979. Youngest of 4 children. At first doctors announced me as healthy and I was placed in a crib ready for whatever life threw my way. Then my godmother (Aunty) who was a nurse was watching over the crib and said to the nurses “What’s wrong with Christie?” The nurse said “Nothing why?” (Aunty) “Take a closer look she’s blue in the face.”

From there my brother became excited running through the hospital singing at the top of his lungs “I’ve got a baby brother.” He was then corrected and told he actually had another sister (1 of 3).

The doctors detected the heart murmur then flew me via air ambulance from Cootamundra to the old Camperdown Children’s Hospital where my parents were told to take me home, treat me like a “normal” child but I’ll only be around 30 days.

Well obviously I surpassed the 30 days the doctors said. I was slow developing as a child. I believe my teeth didn’t start forming til I was 18mths old. I couldn’t go in a baby bouncer as I would turn blue so mum placed me in a bean bag which seemed to do the trick. I couldn’t feed properly so I was fed via goat’s milk in a bottle.

When I was around 2-3 years old the whole family went on a trip around Australia. We had an oxygen tank for emergencies and a radio to keep in contact with the flying doctors. Thankfully neither was needed during the trip.

At 3 years old I had my first open heart surgery. They repaired the two holes in the heart VSD/ASD and repaired the narrow arteries.

This was followed with a second open heart operation to do further repairs at 5 years old.

I started kindergarten in 1985. School was always a struggle for me and even in kindergarten I had one-on-one assistance to help me achieve a better grasp of the lessons.

Math was always my worst subject with all of my report cards saying “Christie needs to strive better to excel in math.” Geography was also a struggle as I had trouble remembering landmarks and pinpointing where countries were located on the map. But I always enjoyed English and Music classes were enjoyable to me and achieved B’s and A’s in these subjects. I had piano lessons as a child and taught myself to play the guitar.

Friends were hard to make and keep as well. As I went to a mainstream school the other students couldn’t understand why I was so different to them and I was often bullied

I grew up being 40% deaf and had hearing aids from the age of 18months. In year 5 I was given a hearing device called an FM system from Australian Hearing.

The device would attach to my hearing aids and the teacher would wear a microphone around her neck so her voice went directly to the microphone to my hearing aids. My peers would often ridicule me over it and often ask if I could get 2dayfm on my fm system. Looking back it does sound funny but to a young child it can be hurtful.

At 8 years old I was diagnosed with VCFS. I can’t recall the FISH test but I know my siblings and parents were tested as well with none of the showing positive to VCFS.

Also at 8 I had a pharyngoplasty done on the palate which is a procedure to remove extra skin that was blocking the nasal passage making speech hard. I had a blood clot after the surgery so nasty memories of that operation. This was followed up with about 2 year’s speech therapy.continued.....



Family Story – continued

I changed high school 3 times due to bullying. Two catholic schools and finally found peace at the local public school.

The school had a hearing impaired unit and several hearing impaired students so I didn't feel so alone. We even went on deaf camps every year which helped boost my confidence. I'm still friends with the students from the hearing impaired unit to this day.

President's Report (continued)

At the conference we had our AGM. I am so thrilled that we had so many people putting up their hand to be an area representative. The contact details are listed on our website under Local Area Representatives. We are still looking for a South Australian and Northern Territory Rep so if you are located in these areas and would like to volunteer please let us know. The Reps are there to offer support and information on services in the local region. I am hoping this new network will create local support groups, coffee groups etc...

Our fabulous foundation Secretary for 2010/2011 is Louise hall. Louise has designed a Christmas card for the foundation. The card is currently being printed and we will have them available for sale in the coming weeks. So keep this in mind before you head off to the shops to purchase your cards for 2010. The cards are a fabulous way to share your Christmas cheer and raise awareness at the same time.

I must once again congratulate our Media Relations Officer, Lucy Jackson on the community service announcements that were aired on Free TV and Foxtel during July and August. I am still receiving emails and calls from people who saw the commercials.

Our major project for 2010/2011 is our educators guide. Mel and I have been working on it for the last few months. It all started with some valuable information from our Treasurer- Audrey Currie. The booklet is currently being reviewed by many different people and I am sure it has many changes and a bit further to go before we go to print. It has been a very large task that has been very time consuming. Once it has been finalised we will let you know. Thanks to everyone who is helping with this guide.

Whilst I am thanking people I should thank the rest of our committee for their constant dedication to VCFS. Chris and Mary Thorley our Editor and Membership Officers are always working tirelessly to help the foundation. Priscilla Gunton our new Assistant Secretary has been continuing for years to help and give us a perspective of someone who lives with VCFS. Kim Clifton and Lee Tye always help out where they can.

Last thing to mention is the annual VCFS Christmas Picnic. It is to be held on the 12th December at Willoughby Park. It is a BYO everything picnic and we look forward to seeing you all there. See the following pages for details.

So stay, safe, well and have a wonderful few months. I will talk to you on Facebook and Twitter.

Maria Kamper

President

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 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



**VCFS 22q11 Foundation
Christmas Cards**

COMING SOON

**Keep an eye out on our
website**

**www.vcfsfa.org.au
Support the Foundation**

Meet Our Local Reps.

Making a splash locally



It's been a wonderful thing to be a part of the VCFS and 22q Foundation of NSW. When we were informed of Zachariah's diagnosis it was a very traumatic and helpless time of our life. After my crying time I then started to seek other parents who faced the same situation. It was a relief to have my first conversation with Melinda Woods and realised that in fact we weren't alone; there is a whole community out there to connect with.

After some time I very quickly began to recognise that distance from the core group could be a barrier in getting practical help. So I began to look for help locally and found myself educating service providers and other carers about VCFS. I found this to be an exciting challenge and I'd really like to offer some of the ideas and practical ways of making a splash locally.

I always take advantage of awareness week what a great opportunity to really attempt to get the word out there. I always contact the media and press. This could be daunting for some, I recognise that but it's worth giving it a go. Over the three yrs that I've done this, there have been 4 news paper articles and one TV story on WIN News and I always get good feedback from those articles. Even though the TV story was in 2008 I still have people telling me that they saw me on the news and I always pick up a new person affected by VCFS along the way.

I always book a stall at a shopping centre, I usually just pick 2 day's as it's quite a commitment to sit there all day. Once again it's worth it, even if you don't have conversation with everyone you're out there and the word and logo VCFS is getting into people's brains. I also take the brochures to library's, Doctor Surgery's or wherever else is appropriate.

Your preschool/ school is also a great resource in getting the word out there, This year the preschool director where Zachy attends suggested that I write a letter to the parents explaining about what VCFS is. I followed up that idea and supplied all the children with a Percy puzzle sticker.

My next step in making a splash here in the Illawarra is to start a support group right here. I've so far contacted the genetic clinic at the hospital to see if they'd like to facilitate a start of a VCFS group. In September I shall be meeting up with the Kerry to see how we can organise that. I'm excited about that as one person I can only do so much but as a group you can be so much more effective.

In general and for the rest of the year I find myself constantly educating everybody about VCFS. Never underestimate your knowledge about VCFS, you are the expert and be confident when explaining it to others.

Tamar Stanford.

illawarra@vcfsfa.org.au

Advice for New Teachers – Helpful hints for the new school year

An extract from Special Needs Children Guide by [Terri Mauro](#)

I asked you to [share your advice for a teacher just starting out in special education](#), and many readers have submitted heartfelt and useful suggestion. A sampling:

- "You ... have to remember that, although you went to school and earned a degree in teaching, we have earned a degree in our child, and you will never, no matter what level of education you earn, be an expert on my child." – Les Spring
- "Don't begin your relationship with the parents with the position that you have all of the answers and the parents are non-factors in the equation. Approach it from the position of a partnership and you'll get a much better experience all around." – Paul Bahr
- "Don't tell me what my kid can't do; I already know that. Tell me what he DID do, what he figured out on his own, how he surprised you with an answer, anything positive that shows me you WANT to teach him." - Sharon
- "Be warm. Get down on the child's eye level when you're speaking to him/her. You'll find these sweet little people will teach you more than you ever thought you could know." -- Clara's Mom
- "My advice, use every resource, ask questions, be honest, and be part of the team." – Beth's Mom

“There is nothing we receive with so much reluctance as advice- Joseph Addison”

2010 VCFS Conference Report.

Our annual VCFS conference was held at the CHW on August 22nd and I am pleased to report that it was a fantastic success. It's always a good opportunity to mingle, discuss ideas, enjoy a catch up and most importantly, listen to great speakers, hear the latest research results and learn new things regarding VCFS.



The day began at 9am with coffee, bikkies and registration before moving into the auditorium for the first session of speakers. We began with the president's report, followed by Carmen Jarrett who gave an insightful presentation regarding strategies to cope with disability. Russell Fairweather from Choice Employment Solutions followed next and offered lots of advice for those of us with VCFS who are looking to move into the workforce. You can contact Russell at www.choicesolutions.com.au

Linda Campbell and a couple of her students presented next, and inspired us with interesting and positive results from their work at the university. Alison McMurtrie from MULTILIT followed on with solutions you could try to improve literacy skills. Visit www.multilit.com to learn more.

Just before lunch we held our Annual General Meeting. We now have area representatives all around NSW and even in WA! Our new reps will become invaluable in helping to raise awareness of VCFS and offering support in their local areas. I would also like to welcome all new board members and say farewell to those who have chosen to step down. Your input, support and assistance over the years have been invaluable and we all say a massive thank you!

During our lunch of sandwiches, fruit and cake several "round table" discussion groups were taking place. These discussions were informal, general conversations amongst conference attendees and a specialist in some area. Thank you to Neil Nicoll, David Fitzsimmons, Russell Fairweather and Alison McMurtrie for taking the time to provide an ear for our questions and plenty of good advice!

After lunch we heard from our special guest, Sam Bailey. What an incredibly inspiring man Sam is. For those of you who are unfamiliar with Sam, he is a C6/C7 quadriplegic who has defied the odds to become a farmer, pilot, inspirational speaker and best selling author. His next goal is to become the first quadriplegic in the world to fly a helicopter. His down to earth attitude, humour and life experience made for an incredible story, and there were a few damp eyes in the auditorium. It just goes to show that no matter what life throws at you, you can still take life by the horns and make the absolute best of it. Thank you to Maria for organizing Sam to speak, I know we all really enjoyed it. You can see a great photo of Sam with everyone on our website.

The afternoon continued with talks from Neil McWhannell from HeartKids, Honey Heussler a pediatrician from the VCFS Clinic in QLD and a USA Conference Report from Maria and I.

As you can see, our 2010 Conference was a great success. I would like to thank all the specialists for donating their time, our tireless volunteers for their continued support and everyone who attended the conference. It really is a great day to attend and I urge everyone to attend next year! Thank you friends!

SYDNEY WEST | NSW HEALTH
AREA HEALTH SERVICE

For parents of children aged 14-25 who are wishing to seek dental care through the public sector, a new Specialist Clinic is running at Westmead Centre for Oral Health. It is a Transitional Dental Care Clinic which is aimed at medically compromised teenagers & young adults whose medical condition has an impact on their oral health. Teenagers with VCFS often have complex dental needs and would benefit significantly from this multidisciplinary approach and care. A referral from a medical or dental practitioner should be addressed to:

Drs Rebecca Eggers & Anastasia Georgiou
Transitional Care Clinic
Department of Oral Medicine, Oral Pathology & Special Needs
Westmead Centre for Oral Health
Darcy Rd
WESTMEAD NSW 2145



Medical Matters

Dental Care for children with VCFS

Recent research has indicated that children with VCFS are at an increased risk of dental decay and require an intensive dental care program from an early age. Poor oral hygiene and dental disease can impact on your child's general health in a number of ways.

Children with certain types of cardiac anomalies are at risk of infective endocarditis, an infection of the heart that can sometimes be caused by oral bacteria. In addition, if dental caries develops, treatment under general anaesthesia is often required to restore or extract decayed teeth in young children and those not able to cope with treatment in the chair. Therefore, it is ideal if dental disease can be prevented or minimised, and your child is accustomed to the dental environment from an early age.

Salivary Gland Disorders

The main dental concern for children with VCFS is a frequent incidence of salivary hypofunction. This refers to a reduced output of saliva, which may be caused either by absence of the salivary glands, or small glands, leading to an inadequate amount of saliva in the mouth.

Saliva is extremely important in preventing dental caries (decay) and protecting the oral soft tissues. About 70% of children with VCFS have been found to have some form of salivary hypofunction. Often there are no symptoms, and children rarely complain of having a dry mouth. However, you may notice that your child has trouble swallowing a dry biscuit, or needs water regularly throughout a meal to help wash down food. Other signs may be frequently dry and cracked lips or a sticky glue-like film covering the teeth.

Enamel Defects

Another important concern is a high incidence of enamel defects of the teeth, with about half of VCFS children affected. Enamel is formed as part of the tooth structure whilst the tooth is growing in the jawbone. It is normally very hard and acts as a barrier to bacteria, acids and chewing forces in the mouth. The formation of enamel occurs over a long period of time as the different types of teeth grow in the jawbone, both before and after birth up until the age of about 10-12 years. It is very susceptible to general disturbances in the body, such as illnesses & medications.

When the enamel fails to form on the teeth to a normal thickness or hardness, it makes the tooth soft and porous, and decay can start very rapidly once the tooth has grown into the mouth, even if the child's diet and brushing are excellent. Teeth with enamel defects often look to be a normal shape, but can sometimes show areas or spots of chalky white, yellow or brown discolouration. Sometimes these defects are not obvious to the naked eye, however your dentist should be able to detect them when your child has their check-up. Often, your Paediatric Dentist may suggest restoring and protecting these at-risk teeth with a stainless steel crown to prevent the teeth from decay in the future.

Dental Caries

Children with VCFS have a high risk of decay, with the average numbers for decayed, extracted and filled teeth at about 5 times average. High levels of decay can often be attributed to problems with lack of saliva, feeding and swallowing difficulties which can reduce the clearance of food and drink from the mouth or frequent high calorie feeds to maintain weight and general health. Fussy eaters or behavioural concerns can make control of food and drink consumption and brushing your child's teeth very difficult. Whilst many of these concerns are not within your control, there are a few things that can be maintained to help reduce their impact.

Preventing dental disease

The most important way of preventing dental caries is to visit your General Dentist, Paediatric Dentist or Special Needs Dentist early on in your child's life. They will be able to give tips on brushing, diet and apply fluoride treatments to help prevent decay. Brushing your child's teeth can be difficult, but it is important this starts from an early age and is consistent. It is recommended that a parent or carer brushes for the child twice per day. Children's toothpaste can be used until the age of 6, when it should be swapped for adult strength toothpaste.

We would like to see your child from the age of 1 year to help identify any potential risk factors for decay and oral disease. Regular 6 monthly visits are important to help with any anxiety associated with dental visits, and detecting decay at an early stage. Other concerns such as small or missing teeth and the need for orthodontic intervention can also be assessed at these visits.

Dr Rebecca Eggers
Paediatric Dentist

References:

A study of oral health and salivary function in 22q11 deletion syndrome. Eggers R. 2007. MDS University of Sydney.
Morphological appearance and chemical composition of enamel in primary teeth from patients with 22q11 deletion syndrome. Klingberg G. *et.al. European Journal of Oral Sciences* 2005: 133(4); 303-311
Caries-related saliva properties in individuals with 22q11 deletion syndrome. Klingberg *et.al. Oral Surgery Oral Medicine Oral Pathology Oral Radiology & Endodontics* 2007:103(4);497-504

More Medical Matters - Tetralogy of Fallot

(information from the Heart Kids Australia www.heartkids.org.au)

What Is It?

Tetralogy of Fallot accounts for 10% of the cases of congenital heart disease. It is the most common cyanotic (blue) heart defect beyond infancy and involves four (Greek tetra = four) anomalies of the structure of the heart:

- 1) A large ventricular septal defect (VSD), or hole, in the septum (muscle wall) which separates the right and left ventricles
- 2) A narrowing (stenosis) of the outflow tract (infundibular stenosis) from the right ventricle into the pulmonary artery and/or pulmonary valve narrowing .
- 3) The aorta is enlarged and "overrides," or sits directly above, the ventricular septal defect (VSD).
- 4) A thickening of the muscle wall of the right ventricle resulting in a right ventricular hypertrophy (thickening).

A right sided aortic arch is present in 1/4 to 1/3 of patients.

What Are Its Effects?

Tetralogy of Fallot affects boys and girls with equal regularity. There is a wide spectrum of ways in which Tetralogy of Fallot can present.

In some infants and children, it can act more like a simple VSD. In these patients the main problem is too much blood flow. In some infants and children, there can be profound narrowing of the right ventricular outflow tract. Because of the severe narrowing, it is easier for the blood to cross the VSD right-to-left and go out the aorta instead of going to the lungs. If this is the case, the infant or child can become quite blue (cyanotic). In fact, the most severe form of Tetralogy of Fallot is with pulmonary atresia where no blood can cross from the right ventricle to the pulmonary arteries and lungs. In these infants it is necessary to begin a medication (Prostaglandin E1) to help keep open the Ductus Arteriosus (a vessel connecting the aorta to the pulmonary artery that usually closes soon after birth - see PDA) to maintain some bloodflow to the lungs. Babies with Tetralogy of Fallot may experience intermittent spells of extreme cyanosis, termed "tetralogy spells," or hypercyanotic spells. These can be serious and even life-threatening.

How Is It Treated?

To increase blood flow to the lungs, an operation known as a Modified B-T Shunt Procedure can be performed in which a "shunt", or tiny tube made of Gore-Tex® is attached between the aorta (or one of its branches) and the pulmonary artery (or one of its two branches - the left pulmonary artery (LPA) or right Pulmonary Artery (RPA)). Repair of Tetralogy of Fallot is usually done when the infant or child becomes cyanotic (blue). The right ventricular outflow obstruction in Tetralogy is usually progressive and worsens over time. Repair is often done in the first few months of life, though it can be delayed if there is adequate blood flow to the lungs. The infundibular tissue that constricts the outflow tract from the right ventricle into the pulmonary artery is removed .

Also, patches made of homograft (human tissue, stored cold) or synthetic material are used to close the hole between the two ventricles and to widen the opening from the right ventricle into the pulmonary artery .

If a shunt procedure was previously performed, the shunt is removed and circulation proceeds more or less as in a normal heart.

Tetralogy of Fallot and the Adult Patient

Tetralogy patients after surgical repair usually have a murmur of pulmonary insufficiency (diastolic murmur) and residual pulmonary stenosis (systolic). There may also be a murmur of a residual VSD. Besides the evaluation of the murmur, if present, diagnosis is based on electrocardiography (producing an ECG, or electrocardiogram), chest x-ray, MRI (Magnetic Resonance Imaging), echocardiography (producing an echocardiogram), and/or angiography (producing an angiogram).

The chest x-ray will usually reveal a normal-sized heart with a distinctive shape, which is caused by right ventricular hypertrophy. The ECG also shows signs of right ventricular hypertrophy, as well as distinctive conduction abnormalities. The overall anatomy of the heart and the defect itself may be seen on the echocardiogram. Angiograms of the two ventricles and aorta will show important details of blood flow.

In addition to these non-invasive tests, a cardiac catheterization procedure is often performed to accurately determine the anatomy of the pulmonary artery and coronary arteries so that a repair strategy can be devised

If a shunt was inserted during childhood, the pulmonary artery anatomy may have become distorted, which could affect the operation procedure.

Before the development of open-heart surgical techniques, this defect was treated by the insertion of shunts (connecting tubes between heart chambers and/or blood vessels) that increased pulmonary blood flow. Some of these procedures (e.g. the Potts and Waterston shunts) were abandoned because they resulted in excessive pulmonary blood flow that caused various complications. Adults who received these treatments in childhood may have distorted pulmonary arteries or have developed pulmonary vascular obstructive disease (PVOD).

Other patients received the original Blalock-Taussig shunt. As it was composed of the patient's own tissue, this shunt would often enlarge over time and also result in PVOD. Nevertheless, the benefits of the surgical repair of Tetralogy of Fallot make it far superior to all of the shunt procedures, which tend to cause pulmonary hypertension, overload of the left ventricle, and other side effects. Therefore, a repair operation is often performed later in life, resulting in increased tolerance for exercise, the elimination of cyanosis, and other benefits.

Though the prospects for long life are excellent after primary repair, there is a small risk of sudden death. This occurs in between 2 and 6 percent of cases (with resuscitation often possible), and usually seems to be caused by ventricular arrhythmias. The risk of sudden death is linked to normalcy of the right ventricular pressure, size and function

All patients with Tetralogy of Fallot, whether treated or untreated, will be prescribed antibiotics to guard against endocarditis (infection of the heart's internal lining).

Patients after primary surgical repair of Tetralogy in childhood will often require further surgical repairs, especially replacement of the pulmonary valve to minimize right ventricular volume overload as a result of the complete pulmonary insufficiency that is a consequence of the Tetralogy repair.continued

Medical Matters - continued

Arrhythmias

Patients who have undergone the surgical repair of Tetralogy of Fallot are prone to developing arrhythmias later in life, with more than a third of adult patients experiencing atrial arrhythmias. This is especially true for patients who received treatment many years ago. While it is general practice today for the repair operation to be performed quite early in life (often during the first year), it was formerly common to defer the procedure until later in childhood. It has been observed that the older a patient was at the time of the operation, the more likely he or she will be to develop arrhythmias.

Arrhythmias often occur because of the thickening or scarring (fibrosis) of tissue in the right ventricle, the patch repair of the ventricular septal defect, and/or the cutting into and subsequent scarring of ventricular tissue. All of these may slow the conduction of electrical impulses through the heart tissue. Other contributing factors may include the gradual enlargement (dilation) of the right ventricle. Unlike some operations, Tetralogy of Fallot repair rarely results in the dysfunction of the heart's natural pacemaker, the sinoatrial node.

Treatment of arrhythmias in these patients may involve medications (e.g. amiodarone), though other approaches are preferred where possible. Pacemakers or ICDs may be implanted. ICDs (implantable cardioverter defibrillators) detect arrhythmias and shock the heart in order to restore normal rhythm, thus protecting against sudden death and acting as temporary pacemakers. Radiofrequency ablations (non-surgical procedures in which the heart tissue that is causing the arrhythmia is neutralized) are performed, often with much success. Reoperations are sometimes necessary, usually involving the replacement of the pulmonary and/or tricuspid valve.

Exercise Concerns

Those patients with unoperated Tetralogy of Fallot are usually fairly limited in their exercise capacities. The patient who has received effective treatment for this anomaly, in which both ventricles are functioning properly and hemodynamics (blood pressures and saturation of oxygen and other gases) are near normal, may have few exercise restrictions. However, their risk of sudden death needs to be determined before participation in competitive athletics.

Several variables concerning this defect make it imperative that the patient receives regular testing. The presence of residual defects or abnormal hemodynamics will lower the limits of safe exercise. Also, some symptoms may develop over time (e.g. arrhythmias and an increase in the size of the right ventricle) that will affect the tolerance for and safety of strenuous exercise. The age at which the repair operation was performed is a significant factor because the longer the pressure on the right ventricle remained high, the less tolerance for exercise there is likely to be.

Anyone with congenital heart disease, repaired or non-repaired, should consult with their cardiologist about physical activity to review the risks.

Pregnancy Issues

Pregnancy is considered to be high-risk for individuals with cyanotic heart diseases such as Tetralogy of Fallot and is not recommended for individuals with severe untreated forms. There may be a danger of the formation of blood clots, causing strokes in extreme cases, as a woman's blood coagulates more easily during pregnancy. Other changes in circulation may increase right to left shunting, which reduces even further the oxygen supply to the body tissues. This may lead to further complications that pose risks to both mother and child.

Accordingly, the untreated Tetralogy of Fallot patient should not undergo pregnancy, especially if oxygen saturations are below 85%. There is a 30% fetal mortality rate for un-operated Tetralogy of Fallot patients, and maternal mortality may be as high as 15%. However, the woman who receives an effective repair operation prior to pregnancy can expect a good chance of success. If the hemodynamics (blood pressures and saturation of oxygen and other gases) are near normal, then the level of risk will approach that of women with normal hearts.

Careful monitoring by health professionals is imperative during pregnancy. In some cases the increased blood volume may cause heart failure or the development of arrhythmias. Other potential difficulties include pulmonary valve regurgitation, right ventricular dysfunction, and right ventricular outflow tract obstruction. In some cases, minimal activity and bed rest may be recommended, and treatment with anticoagulants and oxygen therapy may be prescribed. Echocardiography is often used to monitor fetal development and Cesarean section may be selected as the safest form of delivery.

Anyone with congenital heart disease, repaired or non-repaired, should consult with their cardiologist prior to becoming pregnant to review the risks.

Hypoparathyroidism (Hypoparathyroidism Association)

Hypoparathyroidism is a disorder that causes lower than normal levels of calcium in the blood due to insufficient levels of parathyroid hormone. This condition can be inherited, associated with other disorders, or it may result from neck surgery. Hypoparathyroidism affects males and females in equal numbers. It is seen more often in children under 16 and in adults over 40.

Hypoparathyroidism is characterized by weakness, muscle cramps; abnormal sensations such as tingling; burning and numbness (paresthesias) of the hands; excessive nervousness; loss of memory; headaches and uncontrollable cramping muscle movements of the wrists and feet. Other symptoms may be spasms of the facial muscles (Chvostek Sign); the contraction of muscles produced by mild compression of nerves (Trousseau's Sign); malformations of the teeth, including enamel and roots of the teeth; and malformed finger nails. In some hypoparathyroid conditions, there may also be pernicious anemia; dry and coarse skin; patchy hair loss (alopecia); thin, scant eyebrows; patches of skin that have lost pigment (vitiligo); and mental depression.

Around the Globe

A word from the VCFSEF President 2010/2011



"The difference between a successful person and others is not a lack of strength, not a lack of knowledge, but rather in a lack of will." - (Vincent T. Lombardi)

Recognizing and respecting differences in others, and treating everyone like you want them to treat you, will help make our world a better place for everyone. Care... is your best. You don't have to be handicapped to be different. Everyone is different!" - (Kim Peek, inspiration for Rain Main)

Hello, I am Julie Cooper. I have been a nurse for 27 years. The first ten years of my career I worked in the happiest place on earth, the newborn nursery, as a mother baby nurse. I adored my job, but had to resign when my daughter, Katie, was born. I left while I was ahead, since I was too sleep deprived to provide safe care to others. Katie, now 18, has sleep apnea and didn't sleep through a single night until she was 7 ½ years old and she is still alive to talk about it.

Even though we saw many renowned specialists, Katie was not diagnosed with her congenital heart defect, from which she almost died of pneumonia, until she was three years old. I had concerns that Katie might have a syndrome, not knowing about VCFS at that time, and requested that the cardiologist test her for a genetic disorder. She was subsequently diagnosed with VCFS. Katie has numerous medical issues ranging from a submucosal cleft palate to hypoparathyroidism and hypothyroidism. Katie also has scoliosis and deformed feet. She wears hearing aids, glasses, orthotics and sleeps with a CPAP machine.

Being both a nurse and a mom to a child with VCFS gives me insight and a unique perspective and the ability to relate to both professionals and parents. The hardest job that I have had has been raising my daughter, Katie, and dealing with her multiple medical problems.

After Katie was diagnosed with the syndrome, fifteen years ago, I founded the Mid-Atlantic VCFS Support Group. At that time, and still today, I vowed that no one would fall through the cracks like Katie did. I transformed into a person whom was energized and passionate in my effort help enlighten and educate others about this condition. To this day, I am still president of the VCFS Mid-Atlantic Support Group.

I have a thirst for knowledge and information, which is why I find the conferences so beneficial. My goal is to make Katie Cooper the best that she can be. It is my philosophy that everyone has strengths and weaknesses and it is our job, as parents, to find ways to utilize their strengths and passions.

Together, by sharing ideas between parents and professionals, we can help our children live healthy and happy lives. When Katie is happy, which is now more often than not, her smile lights up the room and her joy is contagious. My daughter loves reading, animals (especially her horse and dogs), photography, and volunteering at animal shelters and horse rescue barns. She was accepted into 5 of the 6 four-year local colleges that she applied to last fall. She will be attending McDaniel College, with accommodations, this year as a freshman. The college is far enough from home for her to have independence yet close enough to have her medical needs met.

Many people have asked me why I would agree to volunteer twice to be president, as I was also past president of the educational foundation 10 years ago when we hosted the conference was in Baltimore, Maryland. *"You must be the change you wish to see in the world"* (Gandhi). Maybe it's because my husband considers me am just a glutton for punishment, but, in reality, I hope to make a difference. I have received lots of wonderful feedback, suggestions and support from many at the Salt Lake City conference. I do appreciate your input and, please, continue to feel free to contact me for ideas. I will attempt to include as many ideas as possible in next year's New Jersey conference in order to keep it unique and ever improved.

This is your chance to pitch in and help. Please make your tax deductible donation to the Educational Foundation, or volunteer for the upcoming conference. You can specify your donation for specific areas of the conference such as handouts. Any donation would be greatly appreciated and we are happy to acknowledge it if you wish. Our membership is growing every day and, by attending the conference, you will have a great opportunity to meet new people and take home new information and ideas. Please join our crusade to enlighten families and caregivers, and work with professionals, thus resulting in the strongest knowledge base to help our kids lead the best life possible.

Top 20 reasons to attend the conference in New Brunswick, NJ July 14th-17th 2011.....

1. The North shore, New York and Philadelphia are nearby. Avis has a rental at the hotel so you have an excuse to go sightseeing
2. The hotel has a 24 hour complimentary gym
3. You can meet international people with cute accents
4. Learn from professionals about state of the art research before it is even published.
5. The hotel has a spa for massages, mani-pedis, and much more
6. We will serve cookies, and maybe even milk, if you behavecontinued

Around the Globe - continued

7. You can decorate cards for sick kids in the hospital and feel good about cheering up others
8. The hotel has an indoor pool and you can see who is brave enough to go for a dip
9. Tax free shopping.....YEAH!!!!!!!!!!!!!!
10. It is more fun than reading tabloid magazines while being stuck in the waiting room for hours
11. Your kids will make new friends while you meet new parents and network
12. You can get a drink at the bar located inside the hotel where they have 27 plasma televisions, so no worries about missing the big game.
13. You don't have to make your luxurious pillow topped mattress or bed for a few days
14. You will have a vacation from cooking.
15. You don't have to clean your bathroom while you are away
16. Wi-Fi high speed internet and iPod docking station in your room so you can party all night while playing your music, drinking from the mini bar, and chatting on facebook
17. Coin operated laundry to clean your clothes up from the morning after
18. Coffee and newspaper in the room to wake up from the morning after
19. Because I am the mom and I said so.....that's why
20. And finally.....You won't hear Julie Cooper complain that you didn't attend

Help Prevent Summer Learning Loss!

Crawford Dedman, Vice-President, Operations, Challenging Minds Inc

I know the kids have just returned to school and your back into the routine of packing lunches, getting out the door on time, therapy and after school activities.

We'll don't get to settled into the routine of the next 8 – 10 weeks. The Christmas break is less than 9 weeks away. Yes that's what I said 9 weeks. Before you know it you will be back to trying to figure out how to keep the kids entertained for 6 weeks over summer. I found this article on the challenging minds website and wanted to share it with you.

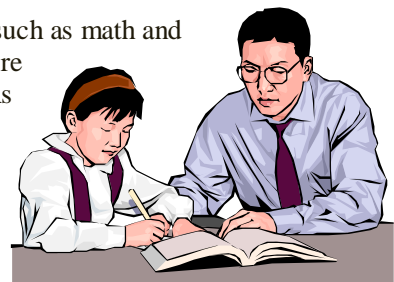
The Christmas holidays are often a carefree, happy time when "kids can be kids" (and parents battle to beat boredom). No school routine!

Experiences such as beach holidays, time with family, trips to museums, parks, and libraries etc... are fun activities, and valuable to every child's health and well being.

However, with the summer can also come "summer learning loss". Children experience learning loss when they do not engage in educational activities during the holidays. This means that a part of what they have spent time learning over the preceding school year evaporates during the summer months.

Most interesting according to research in the USA, is the fact that all students fall behind academically during the Christmas school holidays.

Children and youth lose an average of two months of grade level equivalency in areas such as math and reading. For those students with special education needs their learning loss is often more pronounced. However, summer learning loss is something that you can help prevent. As parents we can provide learning opportunities over the summer their children have the advantage of basic skills practice, and they return to school in the February ready to learn. This can be done with computer games, puzzles, and reading or math challenges.



That is not to say that "summer leisure" should be replaced by "summer school". All it takes is 15 minutes or half an hour every other day or on the weekend. This can really help with memory, reading and writing skills.

The main thing to remember during this time is to relax and enjoy the holiday experience, try not to see these activities as a chore. After all watching a child learn is fabulous, but seeing them retain the information especially those with learning difficulties is inspiring.

family

A D V O C A C Y

News update

Political Candidates Forum has been moved to Monday 25 October at 7.30pm to enable the Minister Peter Primrose, Shadow Minister Andrew Constance and Greens spokesperson Ian Cohen to attend.

You can make an enormous contribution to the campaign by being present on 25 October to demonstrate that the Supported Living Fund is a significant political issue.

Bring your friends!

Venue Ryde Eastwood Leagues Club
117 Ryedale Road
West Ryde NSW 2114

Time 7.30-9 pm

RSVP belinda@family-advocacy.com

Supported
Living
Fund
Campaign



What else can you do?

Ask your local Member of Parliament to raise the issue with the Minister or Shadow Minister

Before 25 October, it is critical that as many people as possible raise the Supported Living Fund with local MPs to secure bipartisan support.

Let Family Advocacy assist you by emailing Belinda at belinda@family-advocacy.com. Or call (02)9869 0866 OR 1800 620 588

If you are not able to attend the Political Candidates Forum, a meeting with your local MP makes your voice heard. If you are attending the Political Candidates Forum, a meeting with your local MP demonstrates the strength of your commitment.

Getting started:

1. Find your electorate
http://www.elections.nsw.gov.au/state_government_elections/electoral_districts/electorate_index
2. Find your local MP
<http://www.parliament.nsw.gov.au/prod/parlment/members.nsf/V3ListCurrentMembers>

Together we can make a difference!

What do we want?

The NSW Government to commit to a **Supported Living Fund** that will enable men and women with disability to establish a home of their own while their family still has capacity to support the transition.

When do we want it?

At the NSW State election, March 2011.

Follow the campaign on facebook <http://www.facebook.com/Supported.Living.Fund>

Show you will attend the event

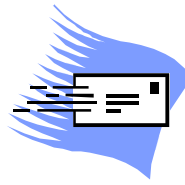
<http://www.facebook.com/Supported.Living.Fund#!/event.php?eid=146866512018608&ref=mf>

----- PO Box 502 Epping NSW 1710 -----
Suite 305 16-18 Cambridge St Epping 2121
ph: 02 9869 0866 Freecall: 1800 620 588 Fax: 02 9869 0722
e-mail: familyadvocacy@family-advocacy.com
web: www.family-advocacy.com

“There is strength in numbers; exciting things happen when you put people with a common interest in the same room.”



Contact Us



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secretary@vcfsfa.org.au

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Local Area Representative

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Local Area Representative

– Illawarra: **Tamar Stanford**

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Local Area Representative

– Victoria: **Laura Cooke**

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Local Area Representative

– Gold Coast: **Emma Parisi**

westernsuburbs@vcfsfa.org.au



VCFS 22q11 Foundation Christmas Picnic
12th December 2010

Willoughby Park, McLelland Street, Willoughby NSW

From 11.30am

BYO Picnic etc....

Email your RSVP to secretary@vcfsfa.org.au

With your children's ages and names for the Santa present

What's On



VCFS & 22q11 Foundation

General Meeting 7th November 2010 10am

Childrens Hospital Westmead

RSVP: Maria Kamper Ph: 9958 2578 president@vcfsfa.org.au

Christmas Party 12th November 2010 11.30am

Willoughby Park, McLelland St Willoughby

RSVP: secretary@vcfsfa.org.au

Learning Links

October 12 & 19 Brain Gym Time 6pm-9pm Cost LLMembers\$170, nonLL members \$183, LLparent members \$93 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

October 13 Developing resilience in children Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

October 14 Teaching writing skills to children with disabilities Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

October 27 Play and learning for children with Autism Spectrum Disorder Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

October 27 Supporting challenging behaviour in school age children Time 6pm-9pm Cost LLMembers\$69, nonLL members \$74, LLparent members \$39 Venue: Learning Links, 43 Reservoir Rd, Mt Pritchard. Registrations: Dana (02) 8568 8200

October 29 Does this child need help? Time 9.30am-4.00pm Cost LL members \$170, Non LL Members \$183, LL Parent Members \$93. Venue: Explore and Develop, 28 Rodborough Rd Frenchs Forest, Registrations: Dana (02) 8568 8200

November 9 Play and learning for children with Autism Spectrum Disorder Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 43 Reservoir Rd, Mt Pritchard. Registrations: Dana (02) 8568 8200

November 10 Ready set Go 2010! Supporting children to separate Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

November 10 Developing resilience in children Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Explore and Develop, 28 Rodborough Rd Frenchs Forest Registrations: Dana (02) 8568 8200

For more information and online booking as well as other topics go to www.learninglinks.com.au

Learning Difficulties Coalition (LDC)

November 1 ADHD Assessment differential diagnosis, co-morbidities and treatment Presented by Dr Daryl Efron Venue: Bankstown Sports Club, Time 7.30pm, Contact 02 9806 9960 info@ldc.org.au

Heart Kids

Regular Events:

Westmead Children's Hospital – Coffee Mornings

1st Tuesday and 3rd Thursday each month. Please contact Kim on 0406 420 627 or 9294 0800 for further details.

Sydney Children's Hospital Randwick – Coffee Morning Contact Karen on 0406 424 620 or 9294 0800.

November 28th Sydney Christmas Party Olympic Park Homebush, Badu Twin Shade Sales site. RSVP Karen Sherlock 0406424620 or email Karen.sherlock@heartkids.org.au

CleftPals NSW

Morning teas If you are interested please email cleftpalsnsw@gmail.com

Family Advocacy For latest information go to www.family-advocacy.com

Addults with ADHD (NSW) Inc

QUARTERLY AWARENESS AFTERNOONS for 2010 Saturdays 2.00pm to 4.30pm:

SUPPORT FOR PARTNERS AND PARENTS OF ADULTS WITH ADHD

Quarterly Luncheons on the last Sunday – 12 noon-2pm

November 28

Venue: Macquarie Hospital 3/51 Wicks Rd Nth Ryde

Email or phone the office 02 9889 5977 / 0416 111 036

AGSA- The Association of Genetic Support of Australasia Inc

November 7 Metropolitan Sydney Carers Seminar A seminar for carers of people with rare genetic conditions. 10.00am – 03.00pm. Venue to be advised. Contact Chiu Lau 02 9211-1462 projects@agsa-geneticsupport.org.au

Carers Australia

Carers Week 17-23 October 2010

“No one is ever too old to know better – Margaret Preston”

Minutes of Meeting Sunday 1 August 2010
Westmead Children's Hospital – Meeting Room

Attendees:

Maria Kamper, Louise Nade, Kim Clifton, Lucy Jackson, Chris Thorley, Mary Thorley, Slade Jenson, Melinda Woods, Audrey Currie

Apologies:

Pricilla Gunton & Leanne Tye

Commenced 10.00am

Banking:

Mel Woods has purchased Quickbooks package

External auditors have been appointed – Quinn Group. Treasurer will write up and provide balance sheets.

It was agreed that MW purchase a laptop and back up hard-drive for the Treasurer.

Membership, donations and all other post to go to one central address - MW to set up a Post Box and have all mail directed to her. If contact ever changes we can get a mail re-direction so we always have the same address that we give to everyone.

AGM: Nominations for positions

Positions have changed; Lucy Jackson resigning as Secretary and taking a new role as Media & PR Representative
Audrey Currie to take over the position of Treasurer after Slade Jenson has resigned.

President – Maria Kamper

Vice President – Mel Woods

Secretary – Louise Nade

Vice Secretary – Position Vacant

Chris Thorley – Editor

Mary Thorley - Membership Secretary

WA Regional Rep – Vanessa Harcourt

VIC Regional Rep – Laura Cook

General Board Members – Slade Jenson, Pricilla Gunton, Kim Clifton, Jason Gray

Mark Kamper will run the voting at the conference.

Conference:

Honey Heussler, Paediatrician from QLD needs to be confirmed in as a speaker at the conference. MW to follow up. It was agreed that the foundation will pay for her flights and taxis.

Tracy Mann will be attending the conference and will say a few words before the AGM.

MK to put the full agenda on to the website.

Awareness Week:

Monday 23 -29 Aug 2010.

An advertising budget of \$10,000 was agreed to – this would include the roll out of the CSA/TV adverts, Newspaper adverts for Awareness Week and Facebook paid adverts for the whole week.

The CSA advert was filmed for free by channel 9 and Lisa Wilkinson. It was produced for free by Tex Whitney Productions and so far we have been given over \$20,000 worth of air time. The incurred costs have come from sending the film via Adstream to the various networks across Australia.

Lucy Jackson to book adverts in print and facebook. Audrey's friend to help with Facebook advertising,

.....continued.....

Minutes continued

Louise Nade to do artwork for Newspaper adverts.

Lucy Jackson has pitched to the Today Show to get a segment during the Awareness Week, Maria Kamper is confirming Dr Linda Campbell and Tracy Mann to see if they will be able to come on to the show.

Maria will put out a short magazine that will include AGM voting form and details of the conference. It will also include 'ideas for VCFS Awareness week' and a colouring in competition for all schools – entries to be sent to new PO Box, Prize – Movie tickets. Louise Nade to design the colouring sheet.

We have a new member from Liverpool that wants to hold a VCFS Fundraising Dinner in October. It was agreed that several board members will attend so they can assist in running the night. The Foundation will buy a table at the dinner in support.

VCFS Education Foundation Conference:

Dr L Campbell replacing Steve Russell from Queensland as the Australian Regional Director with VCFSEF.

Maria Kamper and Louise Nade attended the Salt Lake City conference last month and have written notes and purchased audio tapes of lectures. They will be available to members shortly.

VCFSEF have asked for our Educational booklet to be shared with the global VCFS community and want to translate it in to major languages.

We are sharing our CSA adverts with VCFSEF. Tex Whitney to change the advert to show their website but it must mention 'Proudly sponsored by VCFS 22q11 Foundation, logo/Percy Puzzle'.

Maria suggested holding a VCFSEF conference in Sydney, no sooner than 2015.

2011 Aims:

New Education booklet will be printed late this year to distribute early 2011. Currently covers ages 3-12 but we need more input regarding Leaving School/Further Education –experienced parents such as Pricilla, Leanne, Mary & Chris to assist where possible.

VCFS general booklet needs to be distributed again in 2011 to genetics teams, hospitals, cleft palates, cardiology, immunologists and other relevant contacts.

Grant – SJ & MK to write for assistance in financing new School Starter booklet

Maria to contact 60 minutes and follow up on last years possible story.

2011 will not have a fundraising dinner so we need to come up with another great fun draising initiative – suggests welcome. MK suggested Tumberlong Park, Darling Harbour – Fun Day/Market Day. Please email all ideas to MK.

Louise Nade to Trade Mark Percy Puzzle.

Dental segment of the brochure to be re-written before we re-print. Recommend all areas are reviewed before we reprint

Slade Jenson to investigate how we get on to the government agenda for disability as most other syndromes are listed for financial assistance but not VCFS which is far more prevalent. Slade to send his draft letter for VCFS Recognition to Maria Kamper .

Conference 22 August 2010:

Mel Woods mum not able to cater this year so we agreed to a \$1000 catering budget.

Sandwiches, fruit.

Bags – include DVD from MIND institute, brochure, note pad, pen, copy of latest magazine. Maria Kamper to get bags from storage.

It was agreed to update the 2 pull up banners and purchase 2 more new ones. Spend max \$1000. Louise Nade to do artwork. Lucy Jackson to get a hi-res image of the website montage.

Other Business:

1st Dec Special Needs Christmas Party - MK to resend invites.

Meeting closed 12pm

Minutes AGM 22 August 2010

Meeting opened at 11.40am

- President report: Read by Maria, thank you
- Treasurer report: Read by Audrey, thank you
- Voting – run by Mark Kamper

| Position | Nominating | 1st | 2nd | Voted in |
|------------------------|-------------------|-----------------------|-----------------------|-----------------|
| President | Maria Kamper | Melinda Woods | Priscilla Gunton | Yes |
| Vice President | Melinda Woods | Maria Kamper | Louise Hall | Yes |
| Secretary | Louise Hall | Audrey Currie | Maria Kamper | Yes |
| Vice Secretary | Priscilla Gunton | Lucy Jackson | Leanne Tye | Yes |
| Treasurer | Audrey Currie | Melinda Woods | Louise Hall | Yes |
| Magazine Editor | Chris Thorley | Mary Thorley | Leanne Tye | Yes |
| Memberships | Mary Thorley | Audrey Currie | Chris Thorley | Yes |
| Public Relations/Media | Lucy Jackson | Maria Kamper | Melinda Woods | Yes |
| General Board | Andrew Dunkerley | Maria Kamper | Kim Clifton | Yes |
| | Slade Jenson | Maria Kamper | Lucy Jackson | Yes |
| | Jason Grey | Maria Kamper | Priscilla Gunton | Yes |
| | Alan Jackson | Lucy Jackson | Melinda Woods | Yes |
| | | | | |
| | | | | |
| | | | | |
| Learning Diff Col | Maria Kamper | | | Yes |
| Local Area reps | Emma Parisi | | | Yes |
| | Tamar Stamford | South Coast | | Yes |
| | Ruth Neville | Central West/Dubbo | | Yes |
| | Alta Jones | Hunter | | Yes |
| | Laura Cook | Victoria | | Yes |
| | Christie Duff | Campelltown | | Yes |
| | Candy Royall | Blue Mountains | | Yes |
| | Karen Dace | Canberra | | Yes |
| | Belinda Roberts | Southern Highlands | | Yes |
| | Kate Taylor | Brisbane | | Yes |

Meeting closed at 11am