



VCFS & 22q11 Magazine

May 2010

President's Report

WOW! That's the word for our VCFS Pink and Blue Ball. It was fabulous night. My wonderful team spent the day setting up our Ballroom at the Cromer Golf Club. We were so lucky to have so many wonderful donations and assistance from so many people.

From about 7pm people started flooding in, but it wasn't until the rowdy bunch that arrived on the bus we had arranged, when the fun really began. The drinks flowed; the Band (The Spontaneous Mutations) started pumping out the music. Thanks to Callum Staples and his talented team. Our new Ambassador and MC for the night, Tracy Mann had lost her voice, so the fabulous and talented Commonwealth Champion Melinda Gainsford Taylor stepped in and took over proceedings. The room had an air of excitement and happiness. At about 8.30pm our special guest and supporter Lisa Wilkinson arrived to talk to us about why she chose to support VCFS. Apparently Lucy writes a great heart wrenching letter and because of this Lisa Wilkinson is the face of our new VCFS Community Service Announcement (CSA), which will be aired across the Nine Network in August. The CSA was launched at the Ball and everyone was elated by the result. I will soon have it on our website, so stay tuned. Our raffle was drawn by the Mayor of Warringah, Mike Regan. The winners I am happy to say were 1st prize Cathy Natress, 2nd Kim Clifton and 3rd Neil Nicholl. Congratulations. All in all the night was a huge success and we will be able to fulfil our commitment to our 2010 objectives.

In July I will be travelling to the VCFSEF conference in Salt Lake City. I hope to bring back a wealth of knowledge and information to assist all of our members and the foundation. I will report on it at our VCFS 2010 Conference at the Children's Hospital Westmead on the 22nd August.

The Sydney conference is shaping up to be one of our best. We have a special guest, although unrelated to VCFS; who will come along to tell us about his life and the inspiring journey he has been on for many years; he is Sam Bailey (www.sambailey.com.au). Sam's story will be one to teach us about never giving up. As well as this we have Dr Linda Campbell coming to talk about her research at the John Fletcher University in Newcastle, she is also bringing 3 of her students with information they have learned about VCFS. There will also be round table discussions; this is where a professional will facilitate discussions amongst parents, professionals and other interested parties. This discussion groups will be a forum to share information about those with VCFS. The subject matters will be Anxiety and Depression, Speech, and Transition to Work. To register please email Melinda on vicepresident@vcfsfa.org.au.

It was great to see so many members at our VCFS dinner and I look forward to seeing you at the conference in August. You can also join our Facebook group VCFS & 22q11 Foundation. Until then, take care and remember the foundation is here to support you and your family.

Maria Kamper
President

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- **General Meeting**
1st August 2010
- **Conference and**
AGM 22nd August
2010

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

Douglas Brown's Story



My name is Douglas Miles Brown, and this is my story.....

I'm 24 years old and I have lived in Darwin in Australia's Northern Territory for the past 12 years. In the last year, I have been undergoing a range of tests; one of which being a chromosome blood test. The blood test revealed that I have Velocardiofacial

Syndrome which is a deletion on the 22nd chromosome, which has been present since birth.

I was born in Hamilton in 1984, a month premature after my Mum had a difficult pregnancy with gestational diabetes. I had a lot of respiratory problems when I was young, which later developed into asthma. I had a poor immune system and would catch any bug that was going around. I was small for my age, growing slowly and my speech development was slow.

When I was four years of age my family moved to Australia to sail on a yacht, which my parents continue to do today. My sister Marie and I went to lots of different schools throughout our travels up the east coast of Australia. My Mum worked hard helping me with my schoolwork but it was frustrating as I did struggle to learn. My sister did her work alone as she didn't need the help I did. My sister spent lots of time looking after me as our parents worked very hard while we were in port.

Years of speech therapy followed my surgery and school was difficult. I was never a star pupil, and much more inclined to be busy entertaining the other students by being the class clown than buckling down to study. My sister, by contrast, found school much easier. She was an avid reader who read me books and helped me with my school work, as did Mum and Dad. I loved the "Noddy" series of books by Enid Blyton, and I used to know them off by heart.

A cleft palate was fixed with a pharyngoplasty when I was five and a half. It was one of many hospital stays throughout my childhood. I struggled to put on weight and was always skinny. A teacher once asked my Mum if she was feeding me, which made her angry. Most of my first 12 years were spent in and out of every local hospital of every town we lived in (and some we didn't). For much of this time, I was on steroids. A trip back to New Zealand saw me finally stop taking them and within three weeks I had begun putting on lots of weight. I returned home after only three weeks away and continued to pile on weight.

At fifteen years old, I moved off the boat and went boarding in Darwin. With support from my parents, I finished year 10 and spent time working in McDonalds and Hungry Jacks. Working in fast food outlets did not help with my weight issues and my health continued to deteriorate. I managed to gain my car and motorcycle licenses and buy a car and a motorbike through this time, which were big achievements.

Later, through an employment agency, I landed a job as a kitchen hand in a local sports club. This job led to a four years apprenticeship as a chef, which is drawing to a close. It has entailed lots of practical tasks and blocks of work at Charles Darwin University. There are some requirements I have to go back and repeat but have almost finished. I enjoy cooking and am starting to experiment with my own style.

I prefer being by myself and have amassed a large collection of DVDs and games that I like to watch and play on my entertainment system. I love music and have purchased a brand new electric guitar which I hope to learn to play. I have tried to play it and have only managed to frighten my landlord's dogs so far, but I will learn in time.

My face has been mine for 24 years and I don't see anything wrong with it. I feel I have done well in my life and my recent diagnosis has only affirmed that I have beaten the odds. It has not always been easy for me or my family. Kids like me aren't supposed to get university qualifications, hold down good jobs or live happily alone but I have done all that. And for that, I'm pretty proud of myself.

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

Audrey Currie
Definition Gym
Megan Fookes
Ann Evans
Denis Brown - Diageo
Melinda Gainsford Taylor
Angi Mac
DOSH
Melinda Woods
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Dymocks Chatswood
My Fun
Australian Museum
Emily Leiding Weight
Nicholas Robb PGA of Australia
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Energize Health Clubs
Noo Designs
Bannisters & Rick Stein
Envious Handbags
Printa.net
Beautiful Soles
Eye Candy Optics
Red Balloon
Suzanne Gibbs
Frank and Margaret Bichet
Richard Glover
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Golf 4 U
Robert Stephen and Family
Brad Wall Golf
Gordon Hart
Roses Only
Bridge Climb
Gourmet Source
Soft Play Chatswood
Britt Designs
Harmony Pharmacy
Storage King
Business Computer Services
Hatrick Catering
Swissotel
Camden Valley Inn
Israel Smith Photography
Tex Whitney Productions
Captain Cook Cruises
JJ sisters
The Advertising Department
Carrington Hotel
Jodie McGregor Flowers
The Baby Show
Carolyn and Slade Jensen
Johanna Griggs
The Beauty Tutor
Chris & Margaret Hall
King of Knives
Toddler Interpreter
Chrissy L
Krinklewood Wines
Taronga Zoo
Clever Cat
Lisa Wilkinson
Tracy Mann
Creative Cakes by Julie
Lollypotz
Tribe Aveda Lifestyle Salon
Cromer Golf Club
Louise Hall
U Games
David Adler
Lucy Jackson
Uberkate
David Sullivan
Luisa Clare
Veena Gollop Fitness Inside Out
Deans Shortcuts Butchers
Luna Park
Wine Brothers
Delorenzo Hair Care
Matt Nade
Wine Selectors
Guy Leach
Claudio Raschella
Ocean World

“Oh, what a night to remember!”

At the Pink and Blue Fundraiser

Thanks guys for all your hard work behind the scenes. The bus ride itself was an adventure/fun - it was well worth the \$15 per person. The bus driver was a gem, apparently we were meant to get a coach but that driver called in sick and this driver was called at the last minute, he came all the way from the shire, we had a dodgy bus ie air cond didn't work, and we had to wipe the windscreen for the driver on the return journey so he could see! But we got home in one piece and safe and sound!

The bus was right on time, along Windsor Road, while we were waiting we even had fireworks to watch - some one was letting them off at the park opposite and they were rather good! Along the M2 the bus driver asked me did I have the actual address for the next pick up - I said no - he had some vague idea - so had to do an emergency p/call to Mel/Maria. We managed to pick that mob up, no worries, and thankfully those passengers knew where to pick up the next lot. Well what a noisy bus we had become by then! Getting towards our location the bus driver seemed to be getting lost, but thankfully a few of the passengers came up to help - they even got out the gps on their phones! But Lisa (yes a woman!) was the one that saved the day ie she knew Cromer as she worked there, plus she could read the map without the help of glasses! We arrived at our destination, we saw the "Members Only" entrance and thought there must be another one, but there wasn't, so we had to go around the block - and eventually we got there!

What a hoot of night - I got to meet Tracey Mann - and had my photo taken (thanks Maria) - see sometimes there is an advantage of being an adult with the syndrome! I didn't get to meet Melinda - will have to do that next time! We sold lots of raffle tickets and mystery envelope tickets - but they weren't in the envelopes but the vcfs bags - what a good idea! The food was yummy - the atmosphere was fabulous - the music - well what can I say - absolutely wonderful! Thanks Chris and to his fellow band members!

Now for the bus ride home - we almost left a few people inside even though I had shouted to the bus - is everyone here? We had a few stragglers! Lisa came to our rescue again and got us out of Cromer! The people at the back of the bus partied all the way home with the music blaring! As I said earlier the poor bus driver couldn't see as the window was fogging up so we had to help him wipe the window.... we made one wrong turn and he had to turn the bus around in a very small area but managed to do it without hitting anything so that was good!

Love and hugs, Priscilla



Tracy Mann and Priscilla



Sam Bailey to attend VCFS 22q11 Foundation Conference 22nd August 2010

Sam Bailey grew up on a property near Croppa Creek, North West NSW, and dreamt of spending his life on the land. But at only 19 years of age, he suffered severe spinal injuries in a car accident. He was left a C6/C7 quadriplegic. He's paralysed from the chest down with only limited use of his arms and hands, plus an inability to regulate his body temperature.

The medical experts suggested he might no longer be able to fulfil his childhood dream of becoming a farmer but he defied the odds by coming home to the family farm proving everyone wrong. Those early days weren't easy and the one thing that saved Sam's sanity was a Honda Odyssey. It allowed him to get away from the wheelchair for the first time and got him thinking about mobility around the farm. Despite early reservations, he tried a Quad Bike and it was a huge success. In effect it became his 'legs' on the property and taught him a valuable lesson to try everything, even if it seemed impossible. He learnt to drive a car again using hand controls; travelled overseas and even tried snow skiing using a sitski.

Only one major goal was evading him finding a life companion. That was until ABC Radio Rural Reporter Jenny Black came to interview him. Their friendship grew into a very special relationship; and finally Sam proposed to Jenny 'live' on regional radio. The real-life proposal drew an incredible response from ABC listeners across the NSW New England North West. Callers jammed the phone lines and the fax ran out of paper.

Sam and Jenny were married in 1999 and they now help run the family farm at Croppa Creek. Sam's story continues to inspire people across Australia. It delivers powerful messages about the need to try everything, that anything is possible and how to cope when things don't go according to plan. Sam was featured on ABC TV's "Australian Story" in 2000, and again in follow-up stories in 2004 and the ten year reunion program in 2006.

These are just a couple of inspirational stories about Sam, he has many more to share with us at the VCFS & 22q11 Foundation, 2010 conference. Even though his story does not relate to VCFS, he is an inspiration to anyone who has ever had to deal with adversity, challenges and a disability.

Extract taken from www.sambailey.com.au

Callum's Band

At the *Pink and Blue Fundraiser*

All aiming at a future in music, Callum is enrolled with Corey in a Diploma of Music Production at Newcastle TAFE. Callum passed Cert III & IV last year. They have both been performing at local Hotels in Newcastle and sometimes even getting paid. The band for the Ball was pulled together in the last two weeks, which is why they don't have a name. They had with some anxious moments prior to the big night, but were far more relaxed on the trip back to Newcastle than the way down.

They enjoyed the opportunity to entertain everyone at the *Pink & Blue Ball*. Can you please pass on our thanks for giving Callum the opportunity to play. ... Chris Staples



The "22Q's" or "Spontaneous Mutation"

Bass Guitar/Vocals - Ben Pitman, Sax/Keyboard - Callum Staples,
Drums - Hamish White, Lead Guitar/Vocals - Corey Makin

"The generosity of your time is the most valuable gift you can give"- Sara Henderson

VCFS Conference Day and AGM



Where: The Children's Hospital Westmead

Date: Sunday 22 August 2010

This year's conference will take on a new format. We will have a few speakers in the morning followed by discussion groups facilitated by specialists in three different areas.

It will be a more personal chance to sit down and have questions answered for you.

You get to choose which discussion groups you go to.

Conference Sneak Peak

- Dr Linda Campbell, Newcastle University Research progress
- Guest Speaker: Sam Bailey
- VCFSEF Conference 2010 Salt Lake City: Maria Kamper & Louise Hall
- VCFS & 22q11 Foundation AGM and Report
- Round Tables:
 - Anxiety & Depression – Neil Nicholl
 - Speech & The Palate – David Fitzsimons
 - Transition to Work TBA

Lunch is provided so RVSP is essential to vicepresident@vcfsfa.org.au

The agenda will be ready shortly so keep an eye on the website for it. www.vcfsfa.org.au

Poets Corner

Bruno's Poem, by Lucy Jackson

*In the short time that I've known you Bruno,
I've felt so many things.
For nine months I felt you growing strong,
The joy of new beginnings.*

*When I held you for the first time,
My heart has never felt lighter.
But thinking back to that day my son,
I couldn't have imagined you'd be such a fighter.*

*They told me you had problems,
That your heart was wired wrong,
But straight after your operation
They told me it was strong!*

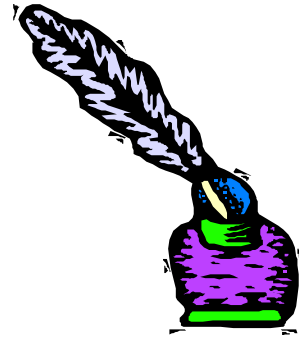
*Since then I have learnt many things
That's made me scared for you.
I keep remembering all the horrible things
That you've already been through.*

*As you start to grow up
You'll have more hurdles to face,
But I will be right by your side,
You know that that's my place.*

*Together we will deal
With the unknown symptoms as they arise.
Don't ever forget how strong you are,
You can see it in your eyes.*

*To have a family like ours,
With Maddie, Daddy and you,
I am the luckiest person I know,
I'm happy because it's true!*

Love Mummy xxx



Luke is good at Tai Kwon Do
Underwater I do handstands
Kangaroos are my favourite animal
Everyone likes my castles



Writing is something Luke enjoys
On the trampoline
On my bike I have fun
Destroying Lego is what I like
Star Wars is the best



By Luke Woods



Just a Mom, like you. By Lisa Ringenberg

You say: Special children are given to special parents-

I am no more special than any other parent. Truth is, sometimes I feel like not running this race and I am barely hanging on. I do not have super powers or special abilities to make this load any easier than if it happened to you or anyone else. My burden is the same as it would be for anyone else, I just don't bore you with the details. Truth be known, many parents given the same circumstances as me, walk away. God didn't pick them as special parents, did he? We are no more special than anyone else.

You say: I don't know if I could do what you do!-

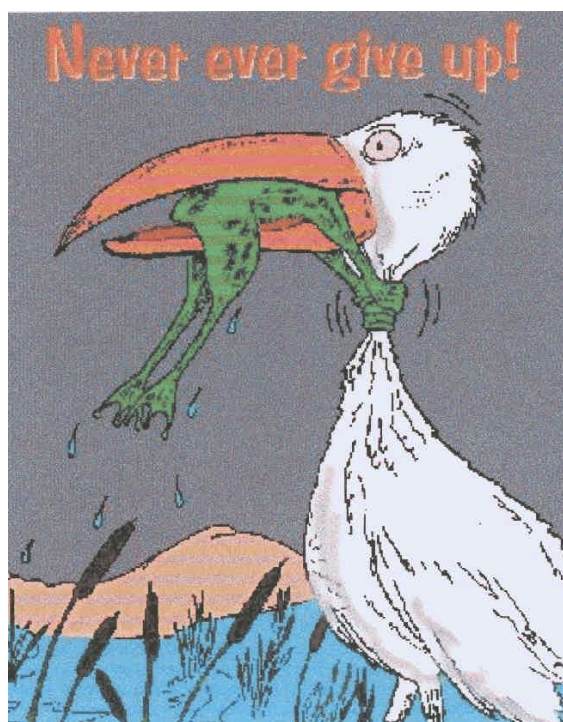
I don't know each day if I will be able to do what I have to either. Can I bare hurting her one more time, or staying in the hospital for another week? I don't know either, but the last time I checked, I had to. My only choice is to lose my daughter to someone else who can step up to the plate, so I have to. There is no choice here. I don't set out to be super woman everyday and see how much I can endure. I don't want to play this game or live this way, I don't choose to, I have to, there is no choice. Do you really think there is a choice involved? Many, many mornings I wake up and think I can't do this anymore.

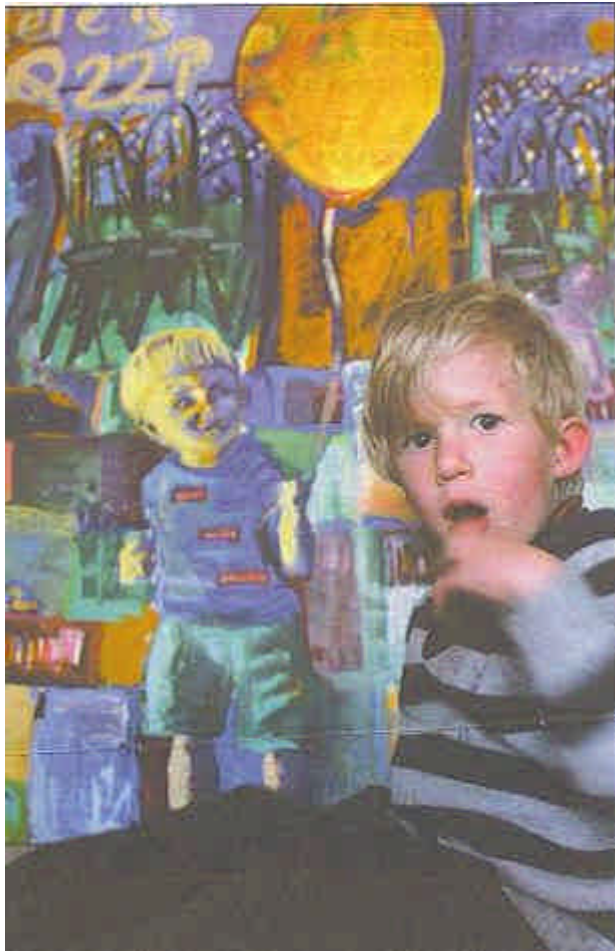
You say: You are always so strong-

No, I am not. Saying so makes me realize that you do not know me. I cry, and I hurt like you would never imagine. I am sick with worry and fear and my own life has past me by while I was hanging onto everyday with my kids. Hoping for just one more day with her. I cry alone, I cry out loud, sometimes I just shed a tear to make a little more room for some other emotion. There is no one who can make this better, I am alone, I am scared, I am not in control and I am beyond sad. I am not strong. You should know that if you think I am strong, you just haven't seen me break down yet. I am not super-human; I am not above it or beyond it. I am like you and it hurts like hell sometimes.

Actually, more often than you probably could imagine.

“We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop” – Mother Theresa





Artists Corner



This is an important painting due to its symbolic nature.

It expresses my reaction to my son's diagnoses of VCFS (velo, cardio, facial, syndrome) aka. Q22.dil.11.2

This image of the child holding the balloon is very significant. Zach is surrounded by bigger things than himself but his focus is up. He is smiling up at the balloon and the balloon is orange like the sun, symbolizing hope and a sunny outlook.

The D.N.A strips are painted red like blood and incidentally it is a blood test that is required to determine whether or not a person has VCFS

The inclusion of the question "where is q22?" promotes another question what is q22? This then leads to an opening to talk about this common, yet little known condition.

Tamar Stanford



Sydney Special Christmas Childrens Party

- WHEN:** Wednesday 1st December 2010
TIME: 10am – 3pm
WHERE: Rosehill Gardens, Rosehill
WHAT: A carnival with lots of rides, roaming performers, games, treats, a full stage show with celebrities and best of all – Santa will be there.
COST: Free

This is a very fun day. It is a Christmas party for special needs children between the ages of 1 and 14 and their immediate family. If you would like to attend please email me your details so I can register you and your kids. I need to know their and their sibling's age and sex so that Santa can give them an appropriate present.

Tickets are limited so please send your **RSVP to me by 18/6/10** so I can send in our foundations registration for the day.

RSVP vicepresident@vcfsfa.org.au or follow the link on the **What's On** page of our website.

Hope you can make it along.

Melinda Woods
Vice President

Photo's-At the *Pink and Blue* Fundraiser



The Team!



Lisa Wilkinson



Melinda Gainsford Taylor



Tracy Mann, Maria, Melinda Gainsford Taylor, Mayor of Warringah Michael Regan, Melinda and Lucy



Across a crowded room!



Medical Matters

IVF- Pre-implantation Genetic Diagnosis

“We are more than the sum of our genes!”

While there are a number of different prenatal tests and procedures available to diagnose the development of a baby, another option where there is a risk that the baby will have a genetic condition is preimplantation genetic diagnosis (PGD).

Some Important points

- PGD involves testing for certain genetic conditions in an embryo created using assisted reproductive technologies (ART) such as in vitro fertilisation (IVF), prior to transferring it to the uterus and allowing it to develop normally
- After hormonal stimulation of the woman's ovaries, some eggs are removed and then fertilised in the laboratory with sperm
- One to two cells are removed from the embryo at the eight cell stage (after 3 days) or at blastocyst stage (after 5 days), for testing
- Only those embryos that do not have the specific genetic condition that was tested for will be transplanted into the woman's uterus
- Usually, no more than one or two embryos will be transferred to the uterus at any one time to avoid the possibility of multiple births (more than one baby in a pregnancy)
- Success rates for having a child from an IVF cycle followed by PGD varies from IVF centre to centre but tend to follow standard IVF success rates
- Like any IVF procedure, stress and often disappointment can accompany PGD. Couples will need to balance the financial and emotional burden of the IVF procedure followed by PGD with that of termination of an affected child conceived naturally
- In Australia, PGD is currently only offered in the private setting

Every woman hopes for a healthy baby. In some cases, the baby may have either a serious physical or intellectual problem.

There are a number of different prenatal (meaning before birth) tests and procedures available to diagnose the development of the baby. Each has advantages, disadvantages and limitations.

Prenatal diagnostic tests include:

1. Ultrasound
2. Chorionic villus sampling (usually simply called CVS)
3. Amniocentesis
4. Cordocentesis

This article discusses a diagnostic pre-pregnancy option called preimplantation genetic diagnosis (PGD) that, with the use of in vitro fertilisation (IVF) therapy, is a diagnostic test performed on an embryo prior to implantation in the uterus.

What is Preimplantation Genetic Diagnosis (PGD)

Preimplantation genetic diagnosis (PGD) was first reported in 1989. It is a very specialised technique that can help couples who are at risk of having a child with a genetic condition avoid doing so without the need for decisions regarding termination of an affected pregnancy.

PGD involves testing an embryo that has been created using assisted reproductive technology (ART) such as in vitro fertilisation (IVF), prior to transferring it to the uterus and allowing it to develop normally.

.....Cont'd

Medical Matters continued.....

How is PGD performed?

Hormones are given to the woman to stimulate her ovaries and enable the collection of a number of eggs or oocytes.

- After the eggs are removed, the eggs are fertilised in the laboratory with sperm
- Those eggs that are successfully fertilised divide and multiply to form a developing embryo called a blastomere
- After three to five days, the developing embryo contains either about eight cells (after three days) or is a blastocyst (after five days)

One or two cells are removed in order to test for the specific genetic condition in question. The removal of these cells does not appear to harm the developing embryo.

Only those embryos that do not have the specific genetic condition tested for will be transplanted into the woman's uterus on the same day, or, in some IVF units, on day five of development.

Usually, no more than one or two embryos will be transferred to the uterus at any one time to avoid the possibility of multiple births.

In some IVF units, unaffected embryos that are not used can be frozen for transfer in another cycle.

What are the advantages and disadvantages of PGD?

Success rates for having a child from an IVF cycle followed by PGD vary from IVF centre to centre but tend to follow standard IVF success rates.

Therefore a pregnancy and an unaffected child cannot be guaranteed using this technique.

It is important for an IVF unit to have a high pregnancy rate to be able to offer reliable preimplantation genetic diagnosis (PGD) with a real chance of achieving pregnancy.

Like any IVF procedure, stress and often disappointment can accompany PGD. Couples will need to balance the financial and emotional cost of the IVF procedure followed by PGD with that of termination of an affected child conceived naturally.

For couples with a moral or religious objection to pregnancy termination and who also have a risk of having a child with a genetic condition, this technique may provide the opportunity to have an unaffected child. In others, PGD may be a preferred option over prenatal testing in a naturally conceived pregnancy. It can also eliminate the possibility of repeated miscarriages for couples where one partner carries a chromosomal translocation.

In Australia, PGD is currently only offered in the private setting. Genetic counseling is important before considering PGD.

Author/s: A/Prof Kristine Barlow-Stewart and Mona Saleh Fact Sheet 18: Preimplantation genetic diagnosis (PGD)

The Centre for Genetics Education (online). www.genetics.edu.au

Name Game In clinical genetics, syndromes are named in a number of different ways.

In some cases, syndromes are named after those who first described them in honour of their scientific contribution. Sometimes syndromes are described symptomatically, by the use of several key findings which appear frequently in affected patients. Some syndromes have been named using acronyms, using the first letters of clinical features associated with the syndrome.

In syndromes which are caused by chromosome rearrangements, syndromes may be named by the type of rearrangement and the chromosome involved.

There have been a small number of syndromes which have been named in other ways, including using the name or initial of the first known patient, after the place or institution where it was first described, or by a specific metabolic fault associated with the syndrome.

There is no general consensus on the best naming system, and as a result, some syndromes are known by more than one name or system.

*Robert J. Shprintzen,
Ph.D. Professor and Director
Center for the Diagnosis, Treatment, and Study of Velo-Cardio-Facial Syndrome
State University of New York Health Science Center at Syracuse*

Example letter: Meet my child for teachers

Charlotte (Charli) Kamper 2010

At aged 4½ Charli was assessed and was diagnosed as having Velo Cardio Facial Syndrome (VCFS). Charli she is currently under review with the Cleft Palate Clinic at the Children's Hospital Westmead (CHW) and had confirmed velo-pharyngeal incompetence (VPI). Charli has undergone intensive speech therapy and her speech is extremely good. Charli is also an outpatient with CHW for Immune Deficiency Disease. Charli receives monthly blood product infusions to boost her immune system. Charli tends to get tired the week leading up to the infusion and her concentration span is reduced. Charli has a hearing impairment which requires her to wear hearing aids. Charli should be placed at the front of a classroom where she can hear the teacher best. Charli wears glasses for long sightedness.

Charli's behaviour is quiet, although when she does warm to people she feels comfortable in conversation and play. She has always been more confident around adults than her peers. She can do things on her own, although she may need a little reminding now and again that she is capable. She will become very shy if things are too loud and overwhelming.

Charli doesn't like to see others hurt or sad and will comfort them, however if Charli is hurt or sad she will not show tell this to her peers and has difficulty expressing this to teachers unless prompted. Giving Charli a regular opportunity to discuss any situations that could be causing her an issue is of great importance.

Generally she is very co-operative, and it is only when something is new or strange that she might become withdrawn. She does have certain eccentricities that you may or may not see at school. She has very strong preferences to certain things and aversions to others, and like most children with VCFS she can be very obsessive if she gets an idea in her head, she will not be easily distracted until she either achieves the result or gets what she desires (a very difficult area indeed).

Charli does have a low IQ and has a mild learning disability. She does pick up new things very quickly and she has an excellent memory, but will often need a gentle push in the right direction. Math's is an area of concern for Charli. She attends weekly Kumon tutoring to assist with this. Charli's reading skills are very good however comprehension is a cause for concern. Charli is a visual learner, so any visual aids that can be used are helpful. Repetitive learning is also very good for Charli.

She can be meticulous and if she wants to achieve something she doesn't give in easily. She doesn't learn well under stress. Charli loves routine and will adhere to rules without fault.

She is very much a creature of habit. She may resist change and the fear of the unknown and it usually takes a little time to adapt to new situations and she will probably observe before joining in. Often this is mistaken for lack of effort.

Charli may appear to have difficulty in following instructions. Charli does understand, however it is difficult for her to process long and complicated lists of instructions. She will also take things literally, which is another VCFS trait. Charli needs short clear and precise instructions to be able to complete a task. Homework should be set out in a clear manner that is not confusing. Step by step instructions can be a massive aid for Charli.

In the classroom Charli may appear to drift away, however this could be because she may not understand the task, the conversation is moving too quickly or she has forgotten what to do. A little prompt will assist.

Charli will often rush a task to complete it in the set time which may cause mistakes to be made. Charli may need to be given a little extra time to complete some tasks. Sometimes Charli may have a tendency to copy other children's work as she has a fear of error. Sometimes the phrase "Charli you can do this" helps to boost her confidence. It is important to remember not to let her off too lightly. We try to encourage her to try every task and we try not to use the phrases "it's too hard" or "I can't" as it gives her an excuse not to try new things.

Making mistakes and being the centre of attention is a huge fear for Charli, as she is aware of her difficulties and if asked a question, she may prefer not to answer. She just wants to be like any other child and just to fit in. Charli does like to stand up and show her peers her work but she needs a lot of practice first and will only do it if she feels confident that she can remember what to say. If she uses prompt cards they usually have a full description of what she wants to say not just key words. Charli needs lead time to practice and prepare for these types of tasks.

As you get to know Charli you will see that she is warm caring individual, who aims to please her teachers and wants to be accepted by her peers. Charli is an independent child and we encourage any activity which will help her to continue leading an independent life.

Currently, Charli catches the bus to and from school. She loves outdoor activities and is a member of the local Cub Scouts. She is second in charge of her pack at cubs. Being put in a position of responsibility often helps Charli rise to a challenge. She is also a member of the local gymnastics club.

Thank you for taking the time to get to know Charli. I have attached some information on VCFS to give you an insight into her condition. This information was written by other parents and teachers of children with VCFS, and may or may not apply to Charli. Charli surprises us regularly with what she is capable of achieving and like all children loves to be praised for good work. .

I will constantly be asking you "how is she getting on", I hope that you don't interpret this and the attached information as being "painful, interfering and over protective parent. I feel that being aware and informed is the best way to assist any child that has special needs. I am always here to help and answer any questions that you may have.

Maria Kamper



GLASSES

With so many of our VCFS children requiring glasses we understand it is sometimes difficult for children to understand why they have to wear glasses when most of their friends don't. Here's how to help keep those glasses where they belong ' on your child's face!

Step 1

Do your best to help your child understand why he or she needs to wear glasses; even some toddlers can understand when you explain that the glasses will help them see better.

Step 2

Let your child help to choose her own frames by offering a selection of frames within your price range. Children won't wear glasses they hate.

Step 3

Avoid buying glasses for your child to grow into ' these will be uncomfortable, as well as less effective than glasses that fit properly.

Step 4

Resort to bribery if necessary. Offer pretty stickers as an incentive to wear glasses, or as a reward for keeping them on for a certain amount of time.

Step 5

Make it clear to your child that certain activities require glasses: If your toddler or preschooler brings you a book, insist that they put her glasses on before you read it.

Step 6

Find some stories or picture books that show children wearing glasses or that deal with the issue of getting glasses.

Step 7

Try to avoid conflicts and battles of will; if your toddler takes their glasses off after half an hour, wait for a while before putting them back on them.

Step 8

Clean the lenses regularly ' your child is more likely to keep them on if she can actually see through them. Show them how to clean them themselves if they're old enough.

Letter to the Editor

Not to sure if you are aware or not, however our son Andrew was able to achieve a lot of accomplishments last week with the Special Olympics in Adelaide. I am not too sure, but I think Andrew may have been the only VCFS person in the Special Olympics. If he is not, he was definitely the only person with VCFS to compete in the Equestrian Demonstration Events - Andrew was able to obtain 3 gold medals and 1 silver medal - this is incredible considering he had never rode the horse before.

Andrew also participated with the Run with the Law Torch relay, which he enjoyed very much.

VCFS children / adults are able to achieve their goals and ambitions with the right guidance and support.

Regards-Raymond Tanner
VCFS / Di George / 22q11.2 DS advocate

“Do what you can, with what you have, where you are”- Theodore Roosevelt

Contact Us



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Minutes

VCFS General meeting 14 march 2010

Present: Melinda Woods, Maria Kamper, Louise Nade, Chris Thorley, Mary Thorley, Priscilla Gunton, Audrey Curry, Slade Jensen

Apologies – Kim Clifton, Leanne tye, Lucy Jackson

Meeting opened 10.05am

- Previous minutes read and accepted by all
- President report read
- Banking –
 - Slade has investigated quick books and will buy this week.
 - We have \$4000 in the operating account and \$67000 in our interest bank account
- Correspondence in read by all
- Website –
 - The new website is up and looks great. Thankyou to Lucy and Boyd Design for all the time and effort.
 - Members area will be changed to a log in area with minutes, newsletters/magazine, members pdf yes list.
- Schools information booklet –
 - VCFS will now be in the NSW dept of education book of disability – contact CHERI to find out what impact this will have on our kids and possible increases in funding for them
 - The first draft of our new education booklet is ready– everyone to read and send comments, will also send to CHERI, Maria taking to US, David, and any other professionals who make like to contribute their knowledge.
 - Meet the child letter is a wonderful initiative – example of this letter will be included in the next magazine
- Memberships
 - Have dropped down need a drive to increase them
 - Update site to make membership form come up and logged online followed by the PayPal button
- Position descriptions and job roles
 - Board member felt unsure of role so we are going to review the job roles and send them out to all board members.
- Research – Linda Campbell, Churchill fellowship
 - Linda has started her new research so encourage members to join the study
 - Maria has applied for the Churchill fellowship. Travel to US and look at all their programs to see if we can bring back the knowledge and apply it to Australia.
- International Conference
 - Proposal of one board member to go to the international conference and report back to our group. We estimate it will cost approx \$4000 to send someone. It should include conference registration, airfare and accommodation. Our bank account must be above a min level. Must also report at the AGM. Mel will write a proposal and send out then we will vote at the next meeting.
- Vcfsef
 - Maria going to put herself up for the VCFSEF board so that we can get the information through as the current Australasian rep is not reporting back.
- Alliances and other foundations
 - ourcommunity.com.au we are now registered with this site
 - not for profit management – registered for the newsletter
 - ensure we are joining groups with similar interests and those sites that give information to charities to help keep us up to date.cont'd

Minutes Continued.....

- Board discussed paying for our president to go the VCFSEF international conference – airfare, accommodation and conference registration. Up to the value of \$4000. Conditions – must report AGM, write for magazine and website.
 - Vote taken to pay up to \$4000 for Maria Kamper to go the VCFSEF Conference everyone in favour.
 - LDC report –
 - Maria is now the LDC VCFS representative on their board. They have asked if we can send them a one page sheet for the VCFS foundation to go on their website (education perspective). Audrey to write, Mel to edit. ASAP
 - Pink and Blue Ball –
 - Still need lots of prizes
 - Audrey's quilt is looking great, she is also donating items embroidered with Percy puzzle
 - Mel to organise bus - \$5 per head will set route (3 or 4 pickup sites) and put details on website.
 - \$65 includes food and drink on arrival
 - Having a champagne raffle \$25 a glass with ticket for a piece of jewellery
 - Callum Staples duet playing as entertainment
 - Tracey Mann – Logie award winner coming as our celebrity MC
 - Lisa Wilkinson – coming at 8.30pm to speak for 10mins
 - \$10 raffle – QLD holiday and passes to QLD parks, shopping gift voucher, cruise
 - Send out raffle tickets – Lou to organise tickets, Mel to write letter to go with it, print books of 5 tickets. Mary, Mel and Lou to stuff envelopes and post to yes list. DL size letter.
 - Tables for auctions are round
 - Mel to buy large balloon letters
 - Prize wrapping day in May
 - I smith has donated prizes, Maria to contact and discuss being a guest
 - Lucy to keep list, Slade to do banking.
 - Conference Day
 - Sam Bailey is confirmed and will speak for about 1 -1 ½ hours – he will be selling his books
 - Discussed having three discussion sessions instead of talks. Need to find three specialists interested in being a part of this.
 - Maria Kamper will present on her trip to the VCFSEF
 - AGM – ask three doctors to join our board as medical advisors
 - Awareness Week
 - This year we will ;
 - Advertise in the newspaper
 - TV ad with Lisa Wilkinson –CH 9 only
 - Update last years TV ad for the other stations
 - Lou to investigate shopper docketts
 - Constitution
 - Need to review it using the checklist from the???? Website.
 - Other business
 - Statement made that for the future should our awareness goals target
 - General population
 - Dr's
 - Government
 - We need to revise what we want to achieve from the awareness campaign. To be discussed in more detail at the next meeting
- Meeting closed 12.05pm

Working Carers' Gateway

Carers of all ages juggle many responsibilities while having to work either full or part time. This can be a real challenge so you might like to check the useful information on this new website. There is a free monthly newsletter with reports, tips and humour, and information.

Check it out at www.workingcarers.org.au

What's On



VCFS & 22q11 Foundation

General Meeting 1st August 2010 10am

Childrens Hospital Westmead

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

Conference and AGM 22nd August 2010 Childrens Hospital Westmead RSVP Maria

Learning Links

June 9, June 16, Teaching children with disabilities about sex and relationships. Time 6pm-830pm Cost LLMembers\$80, nonLL members \$85, LLparent members \$44 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

June 16 ADHD in the early years- understanding and responding. Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue: Learning Links, 88 Shropshire St Miller Registrations: Dana (02) 8568 8200

June 23 Understanding depression and anxiety in children and adolescents Time 6pm-830pm Cost LLMembers\$64, nonLL members \$59, LLparent members \$33 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

July 19 and 26 Working with families who are grieving- issues surrounding diagnosis of a disability in children Time 6pm-9pm Cost LLMembers\$121, nonLL members \$131, LLparent members \$69 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

July 29 Positive practices in the classroom for children with ADHD 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

August 3 Total communication- for children who have difficulty following directions and coping with change 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

August 20 Teaching children with disabilities about sex and relationships. Time 10am- 2pm Cost LLMembers\$80, nonLL members \$85, LLparent members \$44 Venue: Learning Links, 12-14 Pindari Road, Peakhurst Registrations: Dana (02) 8568 8200

September 1 and 8 Working with families who are grieving- issues surrounding diagnosis of a disability in children Time 6pm-9pm Cost LLMembers\$121, nonLL members \$131, LLparent members \$69 Venue: Learning Links, 43 Reservoir Rd, Mt Pritchard. Registrations: Dana (02) 8568 8200

September 6 ADHD in the early years- understanding and responding Time 6pm-830pm Cost LLMembers\$59, nonLL members \$64, LLparent members \$33 Venue Mt Sinai College, 6 Runic Lane, Maroubra 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) For upcoming seminars go to www ldc org au

Heart Kids

June 3, Sex and the City 2 preview/ exclusive charity screening Time 7pm Castle Hill Piazza Cinema. Tickets \$25. Go to www.heartkidsnsw.org.au and download the booking form. Seats are limited and may be booked out at time of publication.

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.

August 14th HeartKids Tiny Tickers Ball 2010 Time 7pm- 1230am The Hilton Hotel 488 George St Sydney Cost \$160 pp members, \$190pp non members. Includes 3 course meal and drinks. RSVP 1st August 2010 Dawn Everingham Ph 0420364125 Fax 02 9834 6841 or email dawn.everingham@heartkids.org.au

CleftPals NSW

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

VCFSEF

July 16- 18 2010, The 17th Annual International Scientific Meeting, Salt Lake City, Utah USA.

For more information and online registration go to www.vcfsef.org

Family Advocacy

June 22 Healthier Lives In Western Sydney. A forum on strategies to improve the health of people with intellectual disabilities in Western Sydney. Time 9am- 3pm Venue Max Webber library Blacktown Cost Including lunch \$10 for family members/carers/students, \$55 for Service Providers, Free for people with intellectual disability. Presented by NSW Council for intellectual Disability www.nswcid.org.au and Western Sydney Intellectual Disability Support Group Inc www.wsidsg.org.au For more information and registration forms (coming soon) go to www.family-advocacy.com or e-mail: familyadvocacy@family-advocacy.com

Addults with ADHD (NSW) Inc

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

June 19 Venue: "The Muse", Sydney Inst. TAFE, Harris Street, Ultimo – Sydney Gold coin donation at the door. Coffee & chat afterwards. All welcome. No need to book. Speaker Dr Ted Cassidy Psychiatrist. More Info at www.add.org.au

SUPPORT FOR PARTNERS AND PARENTS OF ADULTS WITH ADHD

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

June 27, September 26, November 28

Venue: Macquarie Hospital 3/51 Wicks Rd Nth Ryde

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



VCFS & 22q11 Foundation

MEMBERSHIP FORM

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

Please tick

NEW APPLICATION		RENEWAL	
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DETAILS (Please write clearly)

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

AFFECTED INDIVIDUALS OPTIONAL INFORMATION

NAME	GENDER	DOB

Privacy of information

Information included in this form will be made available, as appropriate, to the board of the VCFS & 22q11 Foundation for the purposes of running foundation activities and producing the newsletter. This can include publishing a birthday list, naming individuals in reports of social events or labelling photographs taken at functions. The newsletter is distributed to our membership and contact list.

Please indicate below whether or not you agree to your family's details being used in these ways.

DELETE AS APPLICABLE: (THIS SECTION MUST BE COMPLETED TO ACTIVATE MEMBERSHIP)

- I **do / do not** give permission for the information provided above to be used by the foundation board in the quarterly magazine.
- I **do / do not** give permission to receive fundraising materials such as raffle tickets, invitations to dinners for the purpose of fundraising.
- Please **do / do not** include my details on the contact list. (The contact list is given to all financial members. Many parents have benefited from using this list to share information and experiences and arrange social activities.)
- I **do / do not** give permission for the foundation to contact me on behalf of professionals researching VCFS.

Signature _____ Date _____

ANNUAL MEMBERSHIP FEE IS \$20

Please **enclose \$20** in the form of a cheque or money order made payable to VCFS & 22q11 Foundation or fill in credit card details below which will cover membership until **30 June 2011**.

POST THIS COMPLETED FORM WITH PAYMENT TO

Membership
47 Third Avenue Willoughby NSW 2068
www.vcfsfa.org.au

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

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

TOTAL.....

Credit Card Authorisation

Mastercard or Visa (Please circle) Card Number _____

Cardholders Name _____

Signature _____ Expiry _____/ _____